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ABSTRACT

The first in a series of three publications which address the prevention and treatment of developmental handicaps, this volume includes sections on developmental issues and the consideration of linkages. Section I includes the four following papers: "Early Intervention: The State of the Art" (N. Johnson and H. Chamberlin); "Intellectually Limited Mothers" (R. Kaminer and H. Cohen); "Relationship of Prenatal Care to the Prevention of Mental Retardation and Other Problems of Pregnancy Outcome" (C. Berg and I. Emanuel); and "The Human Cost of Chronic Illness" (H. Ireys and P. Magrab). The second section focuses on existing working arrangements, or linkages, between Title V Maternal and Child Health programs and university affiliated facilities (UAFs) which train personnel in interdisciplinary service delivery, conduct research, and provide services to persons with developmental disabilities and other multiply handicapping conditions. Included in this section are examples of current working relationships and a review of changes occurring within Title V programs that will affect future agreements. (JW)

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DEVELOPMENTAL HANDICAPS: PREVENTION AND TREATMENT

A Cooperative Project
Between University Affiliated Facilities
and State MCH/CC Programs

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This publication has been developed through a collective effort of the national network of University Affiliated Facilities (UAFs) to focus on and expand working relationships between UAFs and Title V Maternal and Child Health programs. The two sections of the book represent two major areas of emphasis for the network.

First, papers have been developed to describe the state of the art (1983) for four topical areas of relevance to handicapped children and their families. These papers are one method for making available the resources of UAFs to Title V programs which have responsibility for serving handicapped persons, such as the state Crippled Children's programs.

The authors' task, to synthesize and select from available research and program information, has been a large assignment. Early intervention programs, for example, have been developed and implemented on a wide scale for twenty years, and the areas of high risk addressed in the paper relating prenatal care to prevention comprise a broad range of conditions and problems. Intellectually limited mothers, on the other hand, are being recognized by health personnel as representing an area of need that is large and is growing, but the extent of the "problem" is not generally known. The authors addressing this area have therefore concentrated on the scope of the problem and on intervention programs, for which there are limited resources and references available. The fouth paper distills the multiple non-financial burdens with which chronically ill and handicapped children and their families must cope and delineates the

roles that UAFs and State MCH/CC programs may assume in collaboratively developing service systems that are responsive to the needs of these children and their families.

The second section of the publication focuses on existing working arrangements, or linkages, between UAFs and Title V programs. Included are some examples of what is currently taking place as well as a look at changes occurring within Title V programs that will affect and shape future linkages and agreements. UAFs and Title V programs, whether those be state programs or Special Projects of Regional and National Significance (SPRANS) have, to a great extent, just begun to explore the multitude of ways in which they can work together.

The examples described here range from sharing staff to shared research, from provision of staff training to provision of contracted services, and from serving on state advisory panels to planning statewide activity. It is hoped that this information will be useful to both UAFs and Title V programs as they seek to develop agreements for working together that are mutually beneficial.

University Affiliated Facilities (UAFs) are programs established to train personnel in the interdisciplinary approach to the delivery of services, to conduct research and to provide exemplary services related to persons with developmental disabilities and other multiply handicapping conditions. There are 51 programs in 37 states and the District of Columbia and many of the UAFs relate to programs in other states.
The American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP) is the national association of UAFs.

I.
DEVELOPMENTAL ISSUES: THE STATE OF THE ART 1983

EARLY INTERVENTION: THE STATE OF THE ART

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Introduction

Although early intervention has been conceived broadly as a strategy for the prevention or remediation of developmental disabilities, there is little consensus about what has to be done, to whom, and when to qualify as early intervention. Indeed, a perusal of the literature indicates that "early" may mean during the very first month of life or as late as three to four years; "intervention" may consist of extra handling or rocking in the neonatal intensive care nursery, a developmental day care program, or an extensive home training program for both infant and parents. The effectiveness of early intervention (an indicator of implicit goals) has been interpreted in terms of keeping a child's development within normal limits, increasing developmental rate, preventing secondary effects of a disability, keeping a child out of an institution, or helping a family to function more adequately.

It is reasonable that the age at which intervention begins, the content of that intervention and the goals of intervention should vary for different children and families in different circumstances. However, caution must be exercised when generalizations are drawn from observations based on one (or several) programs. Comparisons cannot be made nor conclusions on effectiveness drawn in the absence of careful descriptions of target populations, of clearly specified goals, of staff and of the content of the programs in question. If one reads carefully the study of Piper and Pless (1980), who present data to demonstrate that

early intervention is ineffective in remediating the deficits of infants with Down syndrome, and various studies that provide evidence that early intervention is effective (e.g., Hanson, 1977), the results do not appear contradictory. Piper and Pless provided minimal stimulation compared to that in the other studies and over a much shorter period of time. Furthermore, the intervenors in the Piper and Pless study were less experienced in that role and the content of intervention was less clearly defined.

Historical Overview

Perhaps the beginnings of the early intervention movement in this country can be traced to the studies in the late 1930's and 1940's that described the devastating effects of deprivation of a mother figure on the developing infant, that demonstrated the remediating effects of attentive caretakers, and that defined the stimulus properties of an effective child rearing environment. In the 1950's there was a growing body of research which pointed to the beneficial effects of early stimulation in both animals and humans, as well as an accumulation of data on the sensory and learning potential of very young infants. The deprivation hypothesis was developed to explain the effects of poverty on development and compensatory education was seen as a means to mitigate those effects.

This information, along with the social consciousness of the time, led to the Headstart movement of the early 60's, with excitement and optimism about the possibility of remediating the effects of poverty on cognitive ability through preschool stimulation. Initial efforts focused on preparing three and four year old children for school entry and produced significant gains in intellectual ability, although follow-up

data showed that many of these gains were later lost. Research then began to address the effectiveness of the initiation of intervention at much younger ages in stimulation programs that were based in centers or in the children's own homes.

During this same period there was a growing body of data on the plasticity of the infant's central nervous system. Simultaneously, there was a revolution in the care of premature and very sick infants that insured the survival of many that would otherwise have died under previous care regimens, but also subjected these infants to a usually prolonged and presumably depriving early hospital experience. Interest increased in the possibility of preventing developmental disorders in children at risk because of prematurity or other perinatal factors and in the remediation of the effects of known disabilities or handicaps. Studies in hospital premature and intensive care nurseries focused on the provision of tactile-kinesthetic, auditory and multimodal stimulation.

Programs for children with known disabilities sprang up in a variety of hospital, university, rehabilitative and other settings, supported by a federal commitment to services for the mentally retarded and other developmentally disabled individuals. In 1969 Congress enacted P.L. 90-538 which authorized the Handicapped Children's Early Education Program (HCEEP) and created a series of demonstration projects designed to encourage the development of techniques which would assist preschool children to overcome their handicapping conditions.

The early intervention programs for children with known handicaps in the 1960's generally adopted either an education or a medical model, thereby producing some fragmentation of services for infants with complex intervention needs. The move to more interdisciplinary services began in

the early 70's. In 1971 the Bureau of Education for the Handicapped funded the National Collaborative Infant Project to demonstrate exemplary models of service delivery. The project involved an initial consortium of five programs that served children under age two, provided for a pooling of knowledge and was designed to promote a marriage between the medical and psychoeducational disciplines in the provision of comprehensive services. Training in their "transdisciplinary" model was offered to service providers nationwide. Although many programs today remain primarily educational or medical because of their location and/or the expense of an interdisciplinary staff, there appears to be widespread recognition that an interdisciplinary approach is necessary. This is reflected not only in the composition of the staff in treatment programs but in changes in the curricula used to prepare service providers. Many medical, physical therapy and occupational therapy programs are beginning to require courses in psycho-educational developmental perspectives, just as many early childhood education and psychology programs require courses in neurological and motor development.

Characterized by shrinking resources, the last decade has given rise to serious question about the efficacy and cost effectiveness of early intervention. Early optimism and enthusiasm have been tempered by ambiguous data. Many early gains appear to be lost, both in at risk populations (environmental and biological) and in groups of children with known handicaps. The number of programs continues to grow but, to some extent, attention has been shifted from the child as the sole focus of intervention to a more ecological perspective when the family and community systems are considered a part of the intervention system. "Evaluation" and "Accountability" are words seen often in program

proposals, in evaluations of these proposals, and in workshops and academic courses for service personnel. The challenge of the next decade is to gain scientific respectability for early intervention.

The State of the Art

To begin to evaluate early intervention efforts and thereby determine the current state of the art, it is necessary to define the critical paramaters in early intervention, i.e., who is doing what to whom, when, for how long, and for what purpose.

The Parameters of Intervention

Who: the service providers. In the preface to the book emanating from the meeting of the President's Committee on Mental Retardation in 1974, Tjossem and Stephens (1976) stated, "The major professions with the responsibilities and capabilities for the delivery of early intervention services are education, nursing and medicine" (p. xxvi). In the ensuing years early intervention has continued to rely on these disciplines but has expanded to include physical and occupational therapists, psychologists, speech clinicians, social workers and child development specialists. Regardless of the extent to which a setting is interdisciplinary or transdisciplinary in orientation, early intervention is apt to have a different character when provided by a physical therapist than when provided by an educator or a speech clinician. Likewise, there will be a difference when it is provided by two educators, one trained in behavioral methodology and the other in neurodevelopmental theory. Any careful study of an intervention program should include a specification of the characteristics of the intervenors, a practice that is ignored in most current literature.

What: the content of intervention. Apart from the impact of professional orientation and skills, there are other important variables that determine what is characterized as intervention. The intervention setting is one such variable. If the intervention takes place in the home, the parent is more likely to be seen as the primary agent of change and efforts will be directed at teaching the parent therapeutic and teaching techniques rather than at providing specific therapies for the child. In a center based program intervention is usually more systematic and concentrated than in the home. The characteristics of the children who are the targets of intervention are also a critical determinant of the approach used, since their perceived needs form the focus of the treatment or education program.

To Whom: the targets of intervention. Children who are at risk for developmental problems because of the socioeconomic status of their parents are biologically quite different from children at risk because of prematurity or other medical complications early in life. Even more different are children with known genetic, neurologic or sensory impairments. It is unreasonable to assume that all will benefit from the same educational or therapeutic program; neither is it reasonable to expect that parents will be equally motivated or effective in carrying out their part of an intervention program. Scientifically sound studies of early intervention are made particularly difficult by the fact that many early intervention programs serve a "garden variety" of children, these children vary both on the dimension of the nature and severity of the handicap (from "high-risk" to profoundly multiply handicapped) and on the dimension of available resources within the family. Combining data from such diverse subjects would make the effectiveness of any particular

intervention approach difficult to demonstrate simply because of the variability in all measures. Furthermore, no one intervention is appropriate to all children. Each program must be individually tailored, thus requiring single subject designs or some system like Goal Attainment Scaling suggested by Simeonsson (1982).

For What Purpose: The Goal of Intervention. Effectiveness can be assessed only in terms of how well an intervention produces a desired outcome. A review of the literature on early intervention could readily lead one to conclude that mental development is the primary goal of intervention programs, since the primary outcome measures are indices of mental development. This situation exists despite the broad range of child and family support activities that can be observed in any intervention program and despite the vigorous promotion of these activities by the two federal agencies most involved in setting priorities for early intervention programs, the Division of Maternal and Child Health and the Office for Special Education and Rehabilitative Services. Perhaps the situation is more a result of measurement problems than of narrow goals for intervention. Programs are required to be accountable by demonstrating measurable effects of intervention. Respected standardized instruments exist for the measurement of cognitive gains. Few accepted instruments exist for the measurement of progress by parents as they learn to care for a handicapped child. None exist for the measurement of progress in the dynamic system that includes the handicapped child and his/her parents and siblings.

The Effectiveness of Early Intervention

Socioeconomic High Risk Populations. Probably the best data available on the effects of early intervention come from the study of populations at risk for mental retardation because of socioeconomic

conditions. This is in part because the availability and characteristics of this population have made it relatively easy to adopt good scientific methodology (i.e., experimental and control groups randomly assigned or matched on critical variables) and in part because the goal for the intervention is related to established measures. That is, the goal is to promote normal mental development and there are a variety of well standardized instruments for measuring mental development, although there is a question about how well these relate to later measures of intelligence (Johnson, 1982).

In a 1978 review in Pediatric Annals, Haskins, et al. came to the following conclusions: early education or stimulation programs for socioeconomic high risk youngsters have been shown to be effective in maintaining near normal intellectual growth in the preschool years; many gains in IQ appear to be lost after school entry; and there is some evidence that inclusion of mothers in the intervention program yields longer lasting results. They also noted that, in addition to IQ change, some authors report differences between experimental and control groups in other behaviors that might relate to success: task persistence, resistance to distraction, and curiosity.

A more recent report by Lazar and Darlington (1982) presents follow-up data on twelve independently designed and implemented preschool programs of the 1960's. Graduates of these preschool programs were evaluated, some as young as 9 years of age and some as old at 19 at the time of follow-up. In addition to IQ, the investigators compared these children to control or comparable non-intervention groups on achievement test scores, other indicators of school competence (such as, assignment to special education or repetition of a grade), and the attitudes and

values of both the children and their families. The data indicate:

1. Controlling for family background and initial ability, program graduates were significantly less likely to be assigned to special education or retained than controls. This was true regardless of sex or ethnic background.

2. Program graduates retained higher IQ's for several years after the program ended. Actual school achievement was better but not significantly so.

3. Program graduates were more likely to give achievement-related reasons for being proud of themselves.

4. Mothers of program graduates had higher vocational aspirations for their children and more positive attitudes toward school performance (from the authors' abstract).

One of the important points to emerge from this follow-up study is the need to measure variables other than mental ability, even in this population where mental retardation was the specific target of intervention. It was clear in this study that assignment to special education (and thus the label "mentally retarded" in school) is determined not only by IQ but other factors as well. The authors point out that the data indicate that there are two paths to the avoidance of placement in special education. One involves having a normal IQ at age six, a factor strongly influenced by participation in early intervention and by having a mother with a higher educational level. It is also significantly influenced by the presence of a father and of fewer siblings. The second path is simply to participate in early intervention independent of the background factors and IQ at age 6. This strongly suggests that early intervention promotes some adaptive skills, such as

motivation, good conduct and task persistence, that make a child appear more competent and thus are important indicators of effectiveness.

Medically High Risk Populations

The earliest studies on medically high risk populations were done in hospital premature and intensive care nurseries. In a 1981 review of early intervention literature, prepared by INTER-ACT (The National Committee for Services to Very Young Children with Special Needs and Their Families), Garland, et al., (1981) point out that there has been a theoretical difference among researchers as to the specific environmental factors in intensive care nurseries that might contribute to subsequent developmental delay. Operating on the hypothesis that nurseries are deprived environments, some investigators have provided additional stimulation. Others have attempted to intervene by reducing or altering what was felt to be the overstimulation or inappropriate stimulation of around-the-clock bright lights and the bustling activity of the nursery personnel.

In the 1960's data were published that demonstrated the effectiveness of extra holding, stroking, rocking and vestibular stimulation in producing weight gain and more competent responses in high risk infants. The effects, in terms of higher motor scores, were shown to last as long as eight months. These were followed in the 70's with studies of auditory, kinesthetic and visual stimulation and of maternal handling, resulting in data that showed effects at follow-up for as long as one year on the Cattell and Bayley Scales. Such studies have had a major impact on the way that intensive care nurseries are run and on how the parents of the infants in those nurseries are involved in the early lives of their infants. In fact, it is probably fair to say that some of what

was once described as early intervention is now simply considered good nursery management in many intensive care nurseries.

Intervention for medically high risk infants after they leave the hospital has been more difficult to study, in part because it is impossible to control the majority of environmental variables and in part because the mobility of our society makes longitudinal study problematic. Perhaps because of improvements in the technology for dealing with high risk infants, it now appears, however, that most medical problems at birth are less powerful indicators of outcome than socioeconomic conditions and that the majority of medically high risk infants who survive will apparently be normal at 12 months of age without significant intervention beyond the nursery (Campbell and Wilhelm, 1982). These data suggest that intervention for infants at risk because of socioeconomic factors is warranted, particularly if the infants are also at risk medically and that appropriate stimulation of medically high risk infants during their nursery stay is probably helpful. It may be unnecessary, however, to provide intervention for other medically high risk infants until evidence accumulates that specific risk factors merit special attention or unless problems are noted in follow-up care.

Populations with Known Disorders: Down Syndrome. To evaluate the data on the amelioration of the effects of handicapping conditions for children with known genetic, sensory or neurological defects is a difficult task. Research in this area is beset with both ethical and practical problems. The ethical problems revolve around the issue of denial or delay of treatment that might be effective in order to have a control group. This is a particularly critical issue in infant intervention, since it is generally believed that the plasticity of the

organism decreases with age. The practical problems derive from difficulties in matching samples for experimental and control groups, in identifying samples of adequate size, in identifying adequate measures to assess whether the intervention is making a difference on the desired parameters, in dealing with the increased variance produced by health conditions, and in finding financial support for the longitudinal studies that are necessary to document long term effects. In a review of such studies since 1975, Simeonsson et al. (1982) concluded that few studies met the criteria for scientific research, such as specification of inclusion criteria, documentation of reliability, random assignment and/or the use of control/contrast groups.

Perhaps the most widely studied handicapped group in early intervention is that of children with Down syndrome. In the 1970's several studies were published that documented the effectiveness of early intervention in helping Down syndrome infants reach mental, motor and language milestones at a more normal rate than untreated but home-reared infants with Down syndrome. Rarely, however, have adequate control groups been available. Most investigators have compared the progress of treated children with the available literature on home-reared infants. Hanson (1977), for example, presents graphs that compare the attainment of milestones by normal children, Down syndrome children in the University of Oregon program and reported data on Down syndrome children raised at home without intervention. While the non-intervention comparison group was not a control group in the usual sense, the graphs are instructive. They show that not only were the mean values for the intervention children nearer the mean values for normal children than those for the comparison group, but that variability of the children in

the intervention group (ages between which 50% of children accomplished the skill) was similar to the variability of normal children. In contrast, the variability of the non-intervention group was much greater in the case of every milestone passed. For example, there is approximately a five month range within which normal children and the Down syndrome intervention group say "dada" and "mama," with almost identical means, whereas the range reported for non-intervention Down syndrome children is 55 months although the mean is only about 5 months greater. A more typical example is "walks with support." The mean for normal children is around 10 months; for intervention Down syndrome children it is around 15 months; and for non-intervention Down syndrome children it is around 21 months. The variability is 5, 10 and 40 months respectively. What this may suggest is that some home-reared Down syndrome children will progress as well without intervention as with it, but that there are some who will be very delayed without intervention. There has as yet been no effort to identify the factors in the home that most influence the development of the Down syndrome youngster although, on the basis of data in other areas, one would have to suspect that socioeconomic factors may play a major role.

Although Piper and Pless (1980) had a more scientifically respectable experimental and control group, their data is not a convincing refutation of the data presented by other early intervention programs for youngsters with Down syndrome. As noted above, their intervention was truly minimal. The projects that show the most success have involved weekly or daily contact with the youngsters and their families over one or more years of intervention.

Sensory Impairments. Data is more scarce and less persuasive when one studies children with other sorts of biological impairments, largely because of the practical problems noted above that are associated with collecting such data. There have been a few published reports on children with sensory impairments. Early intervention with the deaf has been reported to prevent the development of maladaptive behaviors that contribute to poor integration into society and to increase language complexity and school achievement. In a longitudinal study of blind children, Adelson and Fraiberg (1975) found that intervention children progressed more rapidly than non-intervention children in neuromuscular maturation and postural achievement, with treated children remaining within the range expected for normal children.

Mixed Groups of Handicapping Conditions. With more mixed groups of handicapped infants, data has often been reported in terms of changes in rate of development rather than by comparing experimental and control groups. That is, if a child is assessed at 6 months and is functioning at the 3 months level, he is assumed to be developing at half the normal rate. If at 9 months he is functioning like a 6 month old, he is developing at two-thirds the normal rate. Thus, his rate of development has increased, presumably as a result of intervention. This is a problematic approach both because of the nature of the instruments for measuring development and because of the apparent discontinuity of development itself. Nevertheless, it has been one of the few strategies available to investigators. In their review, Garland, et al. cite the evidence for significant gains in the development of multihandicapped infants after two years of parent/infant education and therapy, with continued learning at improved rates on retesting at ages three and

five. These findings are also supported by the data collected as part of the National Collaborative Infant Project indicating that, across programs and within handicapping conditions, the earlier a child entered an intervention program the better he was functioning at age 3. An exception was noted in the case of severe to profound handicapping conditions where either little progress was made or the instruments used for measurement were insensitive to progress.

In evaluating intervention for severely and multiply handicapped infants, one must particularly question the usefulness of normal developmental measures. In some cases it may be appropriate to consider no regression as an indicator of effectiveness, although this is rarely discussed. In other cases, it may be appropriate to evaluate whether a person is able to live a less restricted life, even if not one just like other people. There is evidence that early intervention with severely and profoundly handicapped children can affect skills that are significant in determining subsequent school or institutional placement. Although Simeonsson et al. (1982) report that only 48% of the studies on early intervention since 1975 provide empirical evidence for effectiveness, they propose that this may be an underestimation for several possible reasons: (1) statistical significance could not be obtained because of limited sample sizes; (2) children may have made progress in developmental domains not measured; (3) children may have made progress in management areas not measured; and (4) there may have been significant changes in the family or other dimensions not specific to the child. These investigators argue for a broader utilization of measures of child characteristics and family adjustment.

Other Effects of Early Intervention

Recently there have been attempts to focus attention on measures other than simple indicators of developmental progress, particularly in an effort to weigh the costs of early intervention against the long range benefits. A survey by the Bureau of Education for the Handicapped of three Handicapped Children's Early Education Program (HCEEP) projects found that the greatest effect of their programs had been on personal social behavior, the least on motor, that two-thirds of the handicapped graduates were in regular school classrooms and that those in regular classrooms were judged as more advanced by their teachers than children with similar handicaps not served in early intervention programs. Similarly, a follow-up of graduates from the University of Washington's Model Preschool Program with various levels of mental retardation and other handicaps had fewer special education placements at school age than similar children who had not experienced early intervention. Both of these studies suggest that within the clearly handicapped population, as well as within the at-risk population, IQ is but one factor that influences special class placement and the expense and stigmata associated with such placements.

Cost Benefit Analyses

Schweinhart and Weikart (1980) present data from the Perry Preschool Project indicating that the cost per child for a two-year preschool program was $5,984 and that children who participated in the project required 50% fewer special education services through highschool than did nonparticipants. They estimate benefits of $14,819 per child based on savings due to a reduced need for special education services, increased lifetime earnings and mothers' ability to return to work while the

children were in preschool.

A somewhat different analysis was done by Garland et al. (1981), based on 940 children from a variety of early intervention programs. They compared the cost of early intervention with the savings accrued by less restrictive placements during the school years, particularly focusing on the ages at which intervention begins. Their data indicate that there are substantial savings when intervention is initiated during the first two years of life. "Compared to a beginning intervention at age six, these preschool programs resulted in a savings from $9,000 to $10,000 per child for the cost of education to age 18" (p. 19).

Impact on Families

In the studies reported thus far, it is clear that most efforts to justify intervention have been based on what happens to the child, usually only in terms of what happens to the child's specific skills, with very little attention paid to what might be described as quality of life issues for the child or his/her family. Studies are now beginning to focus on the extent to which early intervention provides parents with the coping skills that allow them to keep children at home for longer periods of time, resulting in a better life for the child, greater feelings of competence for the parents, and a great savings to taxpayers.

It is obvious that a handicapped child is a family affair and that the effectiveness of intervention must be viewed within this context. Studies of siblings of handicapped children suggest that they have more adjustment problems than siblings of normal children. Moreover, parents of handicapped children are reported to have more restricted social contacts and to suffer more stress. To date little data has been reported on the effects of early intervention on these important

variables. A few studies are cited in the INTER-ACT report that suggest that parents in intervention programs experience increased emotional support, self-esteem, competence and ability to maintain friendships and outside activities.

In order to investigate the nature of stress and social isolation of parents of handicapped children, Saur (1981) compared the family network, family interaction patterns and stress in families with young handicapped children with a matched sample of families with normal children of the same ages. His data do not show significant differences between the groups, contrary to the data and clinical impressions reported for other groups of families of handicapped children. One possible explanation is that the children in Saur's samples were younger than those reported elsewhere. Another important difference, however, is that all of Saur's handicapped children were enrolled in early intervention programs, whereas other samples were not.

New Directions

The early intervention movement is now about twenty years old. It has passed through the bubbling enthusiasm and rapid growth of infancy, the naive optimism of childhood and the self-doubt and defensiveness of adolescence. It is now ready to begin the pursuits of adulthood. Some signs of the directions of the next few years are:

1. There appears to be an acknowledgement that educational intervention, regardless of how early it is begun or how carefully it is programmed, cannot "cure" developmental disabilities, but a concomitant recognition that enhancement of the quality of life for the developmentally disabled person is both a worthy humanitarian goal and a means of saving grief for families and money for society.

handicapped that has evolved out of the recognition that a handicaped person both influences and is influenced by his environment. It is noteworthy that this emphasis appears not only in the activities of front line service programs but in growing support for research on family variables by both the Division of Maternal and Child Health (e.g., Crnic, et al., 1983) and the Office for Special Education and Rehabilitative Services (e.g., Gallagher et al., 1981).

3. Cooperation is beginning to occur between child development specialists who are involved in basic research and interventionists, paving the way for better methodology in early intervention research and for a better understanding of atypical developmental processes. Some investigators who began their careers with the study of cognitive processes in normal childhood are now focusing on the assessment of these processes in the hard to assess, atypical child. Others are considering the effects that specific disorders may have on particular aspects of cognitive development, such as the question of how movement disorders may be detrimental to the development of spatial concepts.

4. In striving to be accountable to both parents and funding agencies, increasing numbers of intervention programs are making major efforts to evaluate their impact on children, on families and on the ultimate cost to society of caring for a handicapped person.

5. New techniques of measuring change through single-subject designs are being developed that may eventually provide the best mechanisms for the evaluation of the effectiveness of early intervention without resorting to experimental and control groups.

Thus, it appears that the next decade will be an exciting time for

the early intervention movement, both in terms of an expansion of knowledge and expertise and in terms of the provision of better services to handicapped infants and their families.

Implications for UAFs and Title V Programs

Early intervention is clearly here to stay, although its character will continue to evolve in the coming years. While a few states have given the responsibility for early intervention to their respective departments of public instruction, for most these services are provided by a variety of programs funded through various private, state and federal agencies, each with its own criteria for eligibility. With shrinking resources for both educational and health services, it will be increasingly important for these resources to be used efficiently. The data clearly indicate that early intervention is most effective if it is continuous and that gains are lost when the intervention is interrupted. Yet, in many states services are disrupted for significant numbers of children. Agencies responsible for maternal and child health services must build bridges with one another and with educational institutions in order to avoid competition for resources and to ensure a smooth transition from one early intervention program to another or from early intervention to public education.

The common problem of inadequate coordination of early intervention services has been recognized for some time. In 1977 the Office (now the Division) of Maternal and Child Health and the Bureau of Education for the Handicapped (now Special Education Program, Office for Special Education and Rehabilitative Services) developed a six state collaborative project to demonstrate that health and education agencies and professionals can work together to provide needed full services to

handicapped children. In all six states changes were made that improved interagency cooperation and enhanced service delivery to these children. In 1978 a Federal Interagency Task Force of six agencies concerned with health and education (including the Division of Maternal and Child Health) supported the development in two states of projects by Head Start aimed at improving services for handicapped children in the 0-5 year age group. In conjunction with these projects, manuals were published to facilitate the development of community based systems of collaboration between service agencies and providers. The American Association of University Affiliated Programs for the Developmentally Disabled (AAUAP), under the leadership of Dr. Phyllis Magrab at Georgetown University, provided consultation to this Task Force (McPherson, 1983).

With the advent of Maternal and Child Health Block Grants in 1981, the states were expected to assume greater responsibility for leadership and increased collaboration became more important. It was hoped that, through the block grants, states could better respond to local needs in the allocation of money. The states have since had time to adjust to greater local control, but in many states lack of interagency cooperation remains a hindrance to the establishment of continuity of services for certain groups of handicapped children and their families. The Division of Maternal and Child Health, through its set aside funds for Special Programs of Regional and National Significance (SPRANS) continues to promote projects that demonstrate collaborative efforts and that can serve as models in solving the problems of interagency cooperation, for example, Project Zero to Three at the National Center for Clinical Infant Programs. The University Affiliated Facilities (UAFs) can also assist in this process by identifying breakdowns in referral and follow-up services

for their individual clients, pinpointing these problems for state agencies and sharing with them as they attempt to alleviate the difficulties.

The state health and education agencies that are charged to provide services to young handicapped children are responsible for designing and staffing programs appropriate to the characteristics of the children and families served. The UAFs can aid these agencies by providing information on the most appropriate intervention practices identified through research and by continuing to play a major role in the provision of trained manpower for the staffing of early intervention programs. They should also continue to share in the provision of trained manpower for the expanding high-risk follow-up screening programs now sponsored by maternal and child health and crippled children's agencies in the majority of states and occasionally shared directly with a UAF. Many infants and young children in need of early intervention services are referred from these screening programs.

It is apparent that many UAFs are already involved in most, or all, of these activities. Several have developed such close interaction with state agencies that they are considered an integral part of the health service delivery system.

In summary, with respect to early intervention, state agencies should be able to turn to the UAF system for trained professionals and for guidance and advice in the planning, management and evaluation of early intervention programs. Although some UAFs will have more expertise in this area than others, it is the intent of the UAF network to facilitate referral of any agency to the most appropriate source for consultation on this or any other problem dealing with the developmentally handicapped.

References

Adelson, E. & Fraiberg, S. Gross motor development in infants blind from birth. In Friedlander, B., Steritt, G. & Kirk, G. (eds.): Exceptional Infant: Assessment and Intervention. Volume 3, New York: Brunner/Mazel, 1975.

Campbell, S. & Wilhelm, I. Developmental sequences in infants at high risk for central nervous system dysfunction: the recovery process in the first year of life. In Stack, J. (ed.): An Interdisciplinary Approach to the Optimal Development of Infants: The Special Child. New York: Human Services Press, 1982.

Crnic, K.A., Ragozin, A.S., Greenberg, M.T., Robinson, N.M. & Basham, R.B. Social interaction and developmental competence of preterm and full-term infants during the first year of life. Child Development, 54, 1983, 1199-1210.

Gallagher, J.J., Beekmon-Bell, P., & Cross, A. Families of handicapped children: sources of stress and its ameleoration. Exceptional Children, 50 (1) 1983, 10-19.

Garland, C., Swanson, J., Sonte, N. & Woodruff, G. (eds.) Early intervention for children with special needs and their families: findings and recommendations. Monmouth, Oregon: Westar Series Paper #11, 1981.

Hanson, M. Teaching your Down's syndrome infant: a guide for parents. Baltimore: University Park Press, 1977.

Haskins, R., Finkelstein, N. & Stedman, D. Infant stimulation programs and their effects. Pediatric Annals, 7, 1978, 123-143.

Johnson, N. Assessment paradigms and atypical infants: an interventionist's perspective. In Bricker, D. (ed.): The Application of Research Findings to Intervention with At-Risk and Handicapped Infants. Baltimore: University Park Press, 1982.

Lazar, I. & Darlington, R. Lasting effects of early education: a report from the consortium for longitudinal studies. Monographs of the Society for Research in Child Development, 47, 1982.

McPherson, M.G. Improving services to infants with handicapping conditions and their families: The Division of Maternal and Child Health as collaborator. Zero to Three, Bulletin of the National Center for Clinical Infant Programs, Vol. IV, No. 1, 1983.

Piper, M. & Pless, I. Early intervention for infants with Down syndrome: a controlled trial. Pediatrics 65, 1980, 463-467.

Saur, W. Social networks and family environments of mothers of multiply, severely handicapped children. Unpublished doctoral dissertation, Florida State University, 1980.

Schweinhart, L.J. & Weikart, D.P. Young Children Grow Up: The Effects of the Perry Preschool Program on Youths through Age 15. Ypsilanti: High/Scope Press, 1980.

Simeonsson, R.J., Cooper, D.H. & Scheiner, A.P. A review and analysis of the effectiveness of early intervention programs. Pediatrics 69, 1982, 635-641.

Tjossem, T.D. & Stephens, B. Preface in Tjossem, T.D. (ed.) Intervention Strategies for High Risk Infants and Young Children. Baltimore: University Park Press, 1976.

A version of this paper which incorporates an expanded set of references is available upon request.

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Introduction

Intellectual limitation on the part of a mother is a risk factor for medical and psychological neglect in her children. The older literature on the subject raised the question of whether mentally retarded individuals should marry and have children. This right is no longer questioned for most mentally retarded people. Therefore, the relevant issue is how to prevent or ameliorate any difficulties experienced by mentally retarded individuals in rearing their children.

A recent review of this topic by Schilling et al. (1982) addresses the question of the correlation between mental retardation in the parent and child maltreatment, and concludes that the literature suggests a relationship. This paper will address the broader question of whether there is a relationship between intellectual limitation on the part of the mother and unfavorable outcome for her children, and, if so, what can be done to improve the mother's effectiveness and mitigate any adverse maternal influences so as to promote normal development for the at risk children. This review will primarily examine the mother's role, since she is the usual focus of intervention, though it is recognized that intellectual limitation on the part of the father also may have biological, economic and/or interactional impact on the children.

The term "intellectual limitation" is used as the preferred one rather than mental retardation, since even reports on deinstitutionalized

populations include individuals with borderline intelligence. The mothers under discussion are primarily in the mildly retarded category, with fewer being moderately retarded or of borderline intelligence; severely and profoundly retarded people seldom have children and, when they do, they are rarely permitted to be primary caretakers of their offspring. Parental IQ below 50 was found to be associated with predominantly unsatisfactory child care by Nickelson (1947) and Shaw and Wright (1960), while Borgman (1969) found the same to be true of mothers with IQs below 60. Intellectual deficits may impede the successful implementation of tasks involving supervision, interaction and organization. These are significant components of the day-to-day skills required for effective mothering. However, social skills and emotional reactions including displays of affection are equally important, but do not correlate as precisely with intelligence. Information on the relevance of social skills to parenting in intellectually limited mothers is available in only a few of the studies.

Scope of the Problem

The prevalence of intellectually limited mothers can only be estimated based on the prevalence rates of mental retardation and the assumption of a birth rate in this population similar to that of the general population. The widely used prevalence rate for mental retardation is 3%. Newer reports from Scandinavia, using different criteria, suggest a lower rate of around 0.5%. The actual figure for the United States may fall somewhere in between these prevalence rates. Using any of the above estimated prevalences, with at least 75% of the total mentally retarded population in the mild category, the number of at risk mothers is considerable. What makes estimating the prevalence even

more difficult is that some mildly retarded individuals may lead sheltered or protected existences and, therefore, produce fewer offspring. However, one report suggests that the opposite pattern may also be operative. Among the deinstitutionalized mothers they studied, Shaw and Wright (1960) found 50% more live births than the norm for women married at the same age and for the same length of time. Scally (1973) reported that the 4,631 known mentally retarded individuals in Northern Ireland produced 791 births, but offered no data on women in the childbearing age and no comparable data for the general population.

Data on the functioning of intellectually limited women as mothers tend to be based on samples which are unrepresentative of this group as a whole. The deinstitutionalized samples are biased by the fact that institutionalization often resulted from the unavailability of a supportive family or from antisocial behavior, rather than simply mental retardation. The institutionalization itself may have significantly affected the behavior of these individuals. Neglectful and abusive mothers brought to the attention of social or medical agencies, and subsequently found to be intellectually limited, are clearly a group whose parenting skills are deficient. While these two groups may be biased in the direction of poorer social skills, a recent report on intellectually limited mothers of developmentally delayed children (Kaminer et al. 1981) may reflect a favorable bias, since the mothers were successful in negotiating the medical care system and following through on a specialty clinic evaluation of their child. It is, therefore, likely that index cases who come to the attention of medical, social or educational agencies are those in whom difficulties are already identified. Situations in which there are no problems are generally unreported.

The child of an intellectually limited mother may be at a disadvantage in numerous ways. A global measure of the sum of these disadvantages is child neglect. Most studies consider a child neglected only when the evidence is overt and conclusive, though it is acknowledged that lesser degrees of inadequacy in child care may have deleterious emotional and cognitive consequences.

Scally (1973) reviewed the case records of all the retarded persons in Northern Ireland who were married or who were single parents. Of the 720 living children, only 30% were apparently reared satisfactorily in their own homes, while 62% had to have other provisions made for them. The issue of child neglect, rather than abuse, emerges as the dominant problem among mentally retarded parents who had been institutionalized or under state guardianship. Of the 90 families with a mentally retarded parent for whom the state of Minnesota assumed guardianship, Mickelson (1947) found that 42% gave satisfactory care, with the remainder providing questionable or unsatisfatory care. Almost one-third of families in Shaw and Wright's (1960) deinstitutionalized sample from Sheffield were known to have required child protective services. Mattinson (1970) reported on 17 couples where both husband and wife were deinstitutionalized from a hospital in southwest England. Of their 40 living children, 6 had been placed away from the parents by the local authorities. Finally, Floor et al. (1975) report on an American cohort of 54 married couples in which one or both partners had been deinstitutionalized. Only one family had a child removed by the court, and another mother, who was single and thus not part of the above cohort, had placed her children in foster care. However, the length and precise nature of the follow-up procedure was not reported. It must be

understood, when examining the data from these reports, that specific criteria for a judgment of abuse and neglect are usually not spelled out, nor is the basis for the decision for removal from the home. It is possible that a bias against the limited parents may exist on the part of professionals and the courts.

Studies of the intelligence of neglectful mothers have shown a disproportionate number of intellectually limited individuals. Sheridan (1960) tested the intelligence of 100 neglectful mothers and found that 27% were retarded and 43% had borderline intelligence. These women had not been institutionalized; in fact, only 2 had attended special schools. Young (1964) reported that 58 of 110 neglectful parents who had psychometric testing were retarded, while Borgman (1969) noted that, among 50 women referred for psychological testing by child welfare workers, those with IQs below 60 almost invariably provided inadequate mothering.

Using a screening instrument based on history, parental literacy and functioning in a clinic contact, Kaminer et al. (1981) identified 45 families as having at least one intellectually limited parent. This represented 12% of the families presenting to a developmental evaluation clinic, located in an inner city environment, for assessment of their child's developmental delay. One fifth of the children were in foster homes, since the parents had proven unable to care for them.

The intellectual development of the offspring of mentally retarded mothers is a matter of concern for both genetic and environmental reasons. Reed and Anderson (1973) have presented data suggesting that the greater sexual freedom for all members of society may lead to increased numbers of intellectually impaired individuals. It is also

known that women with Down syndrome can reproduce, though the number of reported cases are relatively limited. About 50% of their offspring will inherit the same chromosomal defect.

Intellectually limited mothers are usually poor, may have a suboptimal nutritional status, delayed or inadequate prenatal care, particularly if they cannot negotiate the health care system, and may provide inadequate nutrition, medical care and cognitive stimulation for their children. Scally (1973) found a mean social quotient of 89.6 among the 669 offspring of couples in whom the mean social quotient of the mentally retarded parent was 58.

However, most reports indicate a disproportionate number of mentally retarded children when the parents were mentally retarded. Mickelson noted that, based on school achievement, 23% of the at risk children were mentally retarded. Of the liveborn children in Shaw and Wright's sample, 10.6% were mentally retarded. Three of forty, or 7.5%, of Mattinson's cohort were found to be subnormal. In studying a group of lower class mothers, Heber (1968) found that the 45% of mothers who had IQs below 80 accounted for 78% of the children with IQs below 80.

Intellectually limited individuals face many difficulties in coping with the daily tasks of living in the community. Our individualistic, mobile society offers them few restrictions, but also few supports. For those with limited ability to read, to do arithmetic and to tell time, daily activities such as shopping, traveling on public transportation or keeping medical appointments pose a challenge. All of these tasks are essential to the provision of child care, which also demands an awareness of a child's needs and how they change. Based on clinical experience, many workers have noted that, despite their inadequacies,

intellectually limited mothers are often very committed to their maternal roles. They consider motherhood an achievement worthy of pride, one which enhances their self esteem.

Specific issues that have been identified as problem areas for these parents include organizing a household and carrying out tasks such as cooking and laundry. Standards of physical safety, hygienic care and appropriate behavioral management of children are often unfamiliar to the parents. Awareness of the warning signs of illness such as fever, or the overt manifestations of illness such as seizures, may not be interpreted correctly. Difficulties in negotiating the support systems available in the community, such as welfare offices, hospitals and schools, may preclude obtaining essential services. Planning their time and their children's time and budgeting money may present insurmountable obstacles. Having encountered many failures, these individuals often lack self esteem and do not trust their own judgment. If family supports are unavailable, they may form dependent relationships with people who exloit them.

Some factors appear to be associated with better functioning by the mothers and a more favorable outcome for the children. Investment on the mother's part in her role as a mother and a willingness to place the child's needs ahead of her own have been identified by Rosenberg and McTate (1982) as a more important predictor than is intelligence of the ability of a mother to improve her child care skills. Absence of significant emotional problems on the mother's part is as relevant in this population as it is in the general population. Having had experience in providing child care improves performance. We have observed a mother whose neglect of her children necessitated foster care

placement, but in time she became a competent and caring grandmother. Good health on the child's part makes the mother's task easier. Limiting the size of her family helps to keep the mother from being overwhelmed. Mickelson found that the families providing satisfactory care had an average of 2.5 children, while those providing unsatisfactory care averaged 4.2 children. Good intelligence on the child's part may be a mixed blessing. On the one hand, the child can overcome the effects of understimulation and make good developmental progress; on the other hand, a bright curious child may be too demanding for a limited mother and be perceived as overactive and willful. Often a critical factor affecting the mother's ability to cope is the presence of a benefactor, be it a spouse, a family member or a neighbor, who helps in time of crisis or change and carries out the functions the mother cannot perform. If there is no informal benefactor, this role may be adequately filled by the availability of ongoing help and supervision from a medical or social agency.

There appears to be a complex set of interactions between maternal intellectual deficits and unfavorable outcome for children. Child neglect by the mother and an increased incidence of intellectual deficit in children are the outcomes most often studied. Child abuse is also reported, but is far less prevalent. In this regard, it is noteworthy that Friedrich and Boriskin (1976) reported an association between child abuse and the presence of retardation in the child. However, it was not clear whether preexisting retardation is a causative factor in producing abuse. Therefore, a cause and effect relationship has not been established. It is well known that poverty and intellectual deficits are related; therefore, children of limited mothers are almost

invariably also children of poverty. It would thus appear that a host of environmental, medical, economic and social factors may affect the outcome, with intellectual limitation on the part of the mothers being additive to other negative environmental influences that adversely affect the children at risk.

These interrelationships suggest some possible intervention strategies and therapeutic approaches. For example, mothers of children who fail to thrive without organic cause should be considered for an assessment of their intelligence, since intellectual limitation may be a cause of neglect and the latter can be related to undernutrition and poor weight gain. There is clinical evidence that young pregnant teenagers may be more poorly functioning, both academically and intellectually, and that preventive measures could be usefully targeted at this group. Improved nutrition, easily accessible prenatal care, avoidance of substance abuse and family planning efforts to avoid future pregnancies, form some basic components of a primary prevention strategy among this population.

Intervention Programs

Most professionals would agree that the optimal approach would be primary prevention. However, with the exception of the non-pregnant adolescent identified because of medical or psychosocial problems and for whom family planning is possible, most intervention strategies will have to deal with a limited mother and/or developmentally at risk child, one or both of whom are already experiencing difficulties.

In dealing with early identification of problems with child care, there are lessons to be learned from the British system of providing well child follow-up through the use of home visitors. This approach is

well suited for early identification and provision of assistance to limited mothers who may not access supportive services on their own. It is pertinent that the reported American model programs for helping intellectually limited mothers were not primarily linked to the medical care system, the earliest point of entry into any of the generic service systems for the at risk child.

Project ESPRIT, operated by the ARC in Allegheny County, Pennsylvania, serves 25 families where the primary caretaker is mentally retarded and has an infant under 14 months of age judged to be intellectually normal at birth. Services are provided by home visitors and consist of four one hour direct service units per week and occasional parent meetings. Parents are assessed at regular intervals to evaluate parenting skills, independent living skills and safety in the home. The children's development is assessed regularly and, at age 3 years, the child is placed in a preschool program for normal children. Parent advocacy is provided by the home visitor.

Rosenberg and McTate (1982) reported on their work with 8 mentally retarded parents who were part of the Intensive Services to Families at Risk Project which was supported by the Children's Bureau with assistance from the Administration for Children, Youth and Families. The objective was to prevent the need for foster care of abused and neglected children. Methods used were activity groups focusing on skill learning, problem solving and support. A six week mother-child swim group was also used to improve the quality of interaction. The group was intentionally used to meet the parents' social needs as well as improve skills. Home visits and individual counseling sessions were also employed. Four families required substitute placement for their children.

Based on the UCLA Neuropsychiatric Institute's long range follow-up of mentally retarded adults in the community, Tymchuk (1983) has developed a videotape on counseling retarded couples and a curriculum entitled "Thinking about Marriage and Parenting: Effective Decision Making." His group is currently studying how these parents interact with their children and is training them in parenting skills. The curriculum is designed to assist participants in development of their own plan through the use of a videotape demonstrating interaction styles and a series of illustrated booklets.

The Institute is now working with a new group of five families in 20 weekly sessions involving rigorous evaluation of both parents and children, including father-mother-child interaction evaluations. Parents and children are enrolled in a stimulation project while the parents are also learning adequate parenting and marital styles. The program also includes home visits and transportation for participants.

The common denominator applied in these model intervention efforts for intellectually limited parents has been the provision of some concrete help and advocacy around immediate needs prior to initiating parenting instruction. The parental unmet needs for socialization must also be addressed. Mentally retarded mothers often overgeneralize instructions, form overly dependent relationships and need concrete guidance to recognize changed circumstances which require new strategies. In other words, they may need ongoing monitoring of their functioning with the availability of intervention on an as needed basis.

New Directions

Many changes have occurred in recent decades concerning society's views of the rights of mentally retarded individuals. The elimination

of involuntary sterilization and routine guardianship by the state along with the marked decrease in institutionalization have permitted mentally retarded individuals to exercise their autonomy without restriction or coercive protection. Greater sexual freedom and opportunities for child bearing have also increased the number of mentally retarded individuals in the community who may procreate. However, mentally retarded people continue to have difficulties in coping with various social roles, including an important one such as parenting.

In view of this, it would appear reasonable that a system of non-coercive supports be built into the existing social, medical and educational services which mentally retarded individuals already use. Recognition of an individual's intellectual deficit by service providers is an essential step for connecting her with the additional supportive services.

In order to study the child rearing practices of a more representative sample of intellectually limited mothers than previously described, and to provide services to prevent some of the observed harmful outcomes to children, it is necessary to identify parental limitations prior to evidence of their adverse effects. This raises the sensitive issue of screening and identifying mothers as limited at times when the services they are seeking do not relate to their own educational needs. Any screening device applied in a generic service environment or any other situation creates the problem of potentially stigmatizing the parent. This is counterbalanced by the need for a family based approach to service delivery for at risk parents and their offspring using methods which will improve the outcome for the children while helping the parent to cope. Careful screening, and intelligent

and sensitive management, can achieve necessary identification of cases without unnecessary stigmatization.

A screening instrument, The Einstein Parent Screening Instrument, has been developed by Kaminer, Jedrysek and Soles (1981) to identify at risk mothers (Appendix A). The mothers were considered intellectually limited if documentation of retardation or of marked academic deficiency was obtained by history, or if five of the remaining nine items on the screening scale were present. It has been used in a Developmental Evaluation Clinic and in a primary care setting. It requires further validation in a primary care setting. However, screening women in obstetric and pediatric primary care settings is a useful strategy for identification of maternal intellectual deficit per se, rather than identifying the confounding factors such as previous institutionalization, maternal neglect, or the problems of adapting to a developmentally delayed child. It should also be noted that women suspected of being mentally deficient on the basis of the screening instrument, which focuses on cognitive and coping skills, will require additional confirmation of their level of competence. A social service evaluation and a home visitor to explore skills in areas needed for parenting are required. The ESPRIT project also developed some useful instruments in this regard. Complete psychological testing of the mothers is not usually necessary. The critical area requiring intervention is the adequacy of the mother's parenting skills and not her IQ level.

Recommendations

There are many possible approaches to intervention for intellectually limited mothers and their children. The most reasonable

and practical measures are summarized as follows:

1. Appropriate family planning education in special education programs, preferably including parents of teenagers and with a strong linkage to a family planning clinic.

2. In all family planning clinics where girls under 18 years of age are served, brief screening of academic skills and a request for educational information would help to focus attention on the whole patient and provide useful information concerning intellectual achievement and literacy.

3. Obstetric clinics should provide classes in child care and child development for suspect parents.

4. Screening for intellectual limitation of mothers in pediatric primary care settings, using an instrument such as the Einstein Scale or any other validated instrument.

5. Closer follow-up and specialized management of identified mothers.

6. Screening for literacy by welfare workers.

7. Screening of young children for developmental delay, as is performed with instruments such as the Denver Developmental Screening Test. Children of limited mothers are at greater risk of intellectual deficit, and their development requires close follow-up. If a child is identified as delayed on screening, a careful history to ascertain the parents' educational attainment should be part of the evaluation to determine the etiology of the child's developmental delay.

8. Formal assessment of suspect mothers in order to verify the level of difficulty in adaptive functioning and deficits in parenting skills. Psychometric assessment may be required in some cases.

9. Training of medical, social service and other professional staff to identify and work with this population.

Special Techniques for Working with Intellectually Limited Mothers

The following approaches are recommended in working with families in any medical care or social service setting:

Giving Instructions

(1) Do not take anything for granted (e.g. nose drops go in the nose).

(2) Use demonstrations (e.g. show half a teaspoon).

(3) Use a direct manner (e.g. "you must"; "you have to").

(4) Have the mother perform the task in front of you.

(5) Provide immediate feedback.

(6) Check the same skills on subsequent visits.

(7) Reinforce the mother for indicating when she doesn't understand.

More Outreach

(1) Follow-up calls are needed for each failed appointment.

(2) A professional has to make all contacts with other agencies or else nothing may happen.

Family Centered Supports for Mother (and Father)

(1) Use concrete instruction on housekeeping, child care, dealing with emergencies, use of the telephone.

(2) Provide brief written or pictorial list of frequent activities.

(3) Offer homemaker services.

(4) Provide treatment of children, day care, and after school programs.

(5) Provide telephone number to call for assistance when needed.

Professional Attitudes

(1) Professionals must be attuned to the client's limitations.

(2) Address limitations realistically, but matter of factly.

(3) Understand that parents do not get insulted when a realistic approach to delineating their limitations is made, and appropriate guidance given.

(4) Convey your caring attitude more often and in more concrete ways; use praise for ordinary levels of caregiving or for fulfilling normal expectations.

Implication for Title V Public Programs

The intellectually limited mother with a record of failing to obtain prenatal care, using inappropriate child care practices and offering inadequate supervision of her offspring, presents a challenge to public health officials. There is an increased risk of producing handicapped children in these situations and the mechanisms for providing required services and assuring that the child's needs are met are more difficult to establish and implement. The components of Title V Maternal and Child Health Block Grants that are most pertinent to the management of this problem include: (a) adolescent pregnancy programs where at risk situations can be detected; (b) family planning programs with staff trained to deal with intellectually limited mothers; (c) prenatal care provided with adequate outreach efforts to make services available to these at risk mothers with limited capabilities; (d) early identification made available both in the perinatal and postnatal periods for infant and mother pairs who are in need of special help; and (e) direct services offered to the handicapped or developmentally at risk children. The latter programs must include the capability to offer

parent support, particularly in the prescribed format and in a somewhat less traditional manner than is the usual practice.

Though the scope of the problem is unknown and, therefore, the amount of required special services is uncertain, recent reports indicate that many cases are now undetected and the problem may be a much larger one than was realized in the past.

The Role of University Affiliated Facilities

The role of programs with special expertise in dealing with the intellectually limited mothers and their children is readily apparent. Some of the program models and reports pertaining to this problem have originated from the programs that are part of the national network of University Affiliated Programs for the Developmentally Disabled. Some additional studies and/or projects are needed to clarify the most useful approaches to screening and intervention. One starting point in screening could be the examination of illiterate mothers. Screening instruments need to be validated and larger studies of intervention methods are required in order to demonstrate which approaches yield statistically significant benefits. It would appear that University Affiliated Facilities (UAFs) are an appropriate site for continued research and program development to deal with the problem. In addition, UAFs are the logical vehicles for training of personnel to identify and work with both the mothers and the children. The national network of UAFs can also be used to disseminate program accomplishments and research findings to other centers, as well as to governmental agencies and policy makers who have responsibility for developing new services for those in need.

Summary and Conclusion

The problem of intellectually limited mothers and their children who are at risk of developmental disabilities is one that is receiving increasing attention. A screening instrument has been developed to identify mothers with potential problems and some model programs for intervention and training have been tested.

While the extent of the problem is uncertain, there is some evidence that children presenting with developmental problems to Developmental Evaluation and Crippled Children's Clinics have a significant chance of being the offspring of an intellectually limited mother. The latter fact may account for some of the difficulties professionals have in being certain that their recommendations are carried out and that future appointments are kept. Abuse and neglect are also significant potential problems, the scope of which are unknown.

It is evident that future studies are required to determine the prevalence of the problem, to establish procedures for proper identification of high risk situations and to validate screening instruments. More model intervention programs are needed along with studies to assess their effectiveness. Though primary prevention is the optimal approach, the major current emphasis will continue to be on secondary prevention. This can be achieved by early identification of mothers in the medical and social agencies with which they are familiar and intervention to mitigate or eliminate the adverse effects of a suboptimal home environment and inadequate child care practices. Effective approaches consist of offering concrete help, support and training to the mothers and providing intervention or stimulation programs to their children.

CHECKLIST FOR IDENTIFICATION OF INTELLECTUAL LIMITATION IN PARENTS

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1. Cannot travel alone on public transportation; always comes to clin accompanied by another adult

2. Reading and writing problems seen when filling out application:

   a. unable to write
   b. writes minimal factual information only
   c. reads words but with very limited comprehension

3. Erratic appointment keeping (early, late, odd excuses, wrong day)

4. Provides vague or naive information about basic facts

5. Problems managing money

6. Overwhelmed by routine demands

7. Child management difficulty of excessive degree observed or reported

8. Uses covering-up techniques to conceal deficit

9. Central role of a "benefactor"; requires help in areas not expected f adult.

10. Historical information documenting limitation/retardation from:

    a. self-report
    b. family member
    c. social agency

References

Borgman, R.D.: Intelligence and Maternal Inadequacy. New York: Child Welfare League of America, 1969.

Floor L., Baxter, D., Rosen, M. & Zisfein, L.: A survey of marriages among previously institutionalized retardates. Mental Retardation. 13 (2), 1975, 33-37.

Friedrich, W.N. & Boriskin, J.A.: The role of the child in abuse: A review of the literature. American Journal of Orthopsychiatry. 46 (4), 1976, 530-590.

Heber, R., Dever, R. & Conry, J.: The influence of environmental and genetic variables on intellectual development. In Prehm, H.J., Hamerlynck, L.A. & Crosson, J.E. (eds.) Behavioral Research in Mental Retardation. University of Oregon, Eugene, Oregon. Rehabilitation Research and Training Center in Mental Retardation Monograph No. 1, 1968.

Kaminer, R., Jedrysek, E. & Soles, B.: Intellectually limited parents. Developmental and Behavioral Pediatrics. 2 (2), 1981, 39-43.

Mattinson, J.: Marriage and Mental Handicap. Pittsburgh, Pa. University of Pittsburgh Press, 1970.

Mickelson, P.: The feebleminded parent; A study of 90 family cases. American Journal of Mental Deficiency. 51, 1947, 644-653.

Reed, S.C. & Anderson, V.E.: Effects of Changing Sexuality on the Gene Pool. In De La Cruz, F.F. & La Veck, G.D., (eds.) Human Sexuality and the Mentally Retarded. New York, N.Y., Brunner, Mazel, 1973.

Rosenberg, S.A. & McTate, G.A.: Intellectually handicapped mothers: Problems and prospects. Children Today. 11 (1) 1982, 24-26, 37.

Scally, B.G.: Marriage and mental handicap: Some observations in Northern Ireland. In De La Cruz, F.F. & La Veck, G.D., (eds.) Human Sexuality and the Mentally Retarded. New York, N.Y., Brunner, Mazel, 1973.

Schilling, R.F., Schinke, S.P., Blythe, B.J. & Barth, R.P.: Child maltreatment and mentally retarded parents: Is there a relationship? Mental Retardation. 20 (5), 1982, 201-209.

Shaw, C.H. & Wright, C.H.: The married mental defective: A follow up study. The Lancet. 1, 1960, 273-274.

Sherman, L.G. & Flory Jr., R.H.: ESPRIT: Educational System in Parenting for the Retarded with Infants and Toddlers: A Manual for Replication. Unpublished. Distributed to a limited audience for the purpose of replication by Project ESPRIT-ARC Allegheny County, Pa. 1981.

Sheridan, M.D.: The intelligence of 100 neglectful mothers. British Medical Journal. 1, 1956, 91-93.

Tymchuk, A.J.: Marriage counselling with the retarded. Outline of a presentation. UCLA Neuropsychiatric Institute, University of California, Los Angeles, 1983.

Young, L.: Wednesday's Children. A Study of Child Neglect and Abuse. New York, McGraw-Hill, 1964.

RELATIONSHIP OF PRENATAL CARE TO THE PREVENTION OF MENTAL RETARDATION AND OTHER PROBLEMS OF PREGNANCY OUTCOME

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Historical Review

Conventional wisdom holds that in many health problems medical care is preventive. This issue has been addressed relative to prenatal care and its effect on pregnancy outcome. Many studies on this subject have used one or both of two simple independent variables: time of onset of care and number of prenatal visits. Most studies using such variables have found strong crude statistical relationships between early onset of care and good outcome. However, in studies which made adjustments for such variables as gestational duration, age, parity, social class and race, the relationship between early care and/or number of visits either diminished or disappeared (Stanley, 1977). It has been pointed out that the measures used by such studies - time of onset of care and number of visits - are descriptors of maternal behavior and not of the kind of care given (Emanuel, 1976). In fact, there are few studies which look in an adequate way at the specific content of the care (Enkin and Chalmers, 1982). Furthermore, with few exceptions, the outcome variables have been immediate ones, such as fetal death, birth weight, prematurity, Apgar scores, and neonatal death. In the Collaborative Perinatal Project, Broman, Nichols and Kennedy (1975) found that number of prenatal visits and time of onset of care were significantly correlated with IQ at 4

years, even when adjusted for socioeconomic status of the mother. A study of the population of live births in the USA for 1978 related Apgar scores simultaneously to time of onset of care and maternal educational attainment. For women who had any prenatal care, the percent of low one-minute and five-minute Apgar scores was inversely related to maternal educational status. Interestingly, the lowest rate of low Apgar scores occurred among those with 16+ years of education who began care in the 7th to 9th month. However, for those women who had no prenatal care, the relationship was reversed; that is, the higher the educational status the higher the percentage of low scores (Querec, 1981). In another population-based analysis of American births, Taffel (1978) found that while time of onset of prenatal care was directly related to rate of low birth weight, there was a stronger inverse relationship between maternal educational status and low birth weight rates. Such studies indicate that prenatal care alone will not solve the problems of pregnancy outcome, but that maternal characteristics and, probably, life style are important.

An interesting study by Sokol, Woolf, Rosen and Weingarden, (1981) compared pregnancy outcome in two groups of women: those in a Maternal and Infant (M&I) Care Program and a comparable group who qualified for the program but could not participate because of residential restriction. In fact, the M&I group were a higher risk group than the residentially-excluded group based on a standard obstetrical risk score which included both medical and social factors. Both groups received prenantal care and delivered at the same hospital and were cared for by the same providers. The M&I group received additional care which included social services, patient education, nutritional assessment and

counseling, dental services, follow-up of missed appointments, and home visits. In spite of their higher risk status, M&I women had lower perinatal mortality and a lower rate of low birth weight. The authors concluded that since both groups received the same obstetric services, the ancillary services were probably responsible for the better outcomes in the M&I women.

Non-Optimal Pregnancy Outcomes

Because we feel that mental retardation and other developmental disabilities cannot be justifiably separated from overall maternal and child health, this paper will broadly consider non-optimal pregnancy outcomes as the dependent variables. There are many studies that look at developmental sequelae of neonatal intensive care, although few are population-based. However, there are no studies which specifically look at content of prenatal care and long-term child development.

While prematurity and low birth weight (LBW) are related to mental retardation, the relationship is not particularly strong except for very low birth weight (VLBW) babies (Stewart, Reynolds & Lipscomb, 1981). Stanley reported in 1979 that most children with cerebral palsy are not low birth weight babies. While it is important to study the relationship between prenatal care and immediate outcomes such as LBW and prematurity, there is also a pressing need to develop the methodology to do follow-up studies of the relationship between prenatal care and long-term developmental outcomes. The simplistic variables which have been used in many prenatal care studies are clearly inadequate and inappropriate. There are situations in which certain women are at high risk to bear children with developmental disabilities. In some of these situations specific prenatal care practices can prevent or avert the birth of

handicapped children.

In this paper a broad definition of teratology will be used based on Wilson (1973): "... the science dealing with the causes, mechanisms, and manifestations of developmental deviations of either structural or functional nature." Included in this definition are such abnormal outcomes as LBW, prematurity, perinatal mortality, mental retardation, congenital malformations and behavioral disorders.

The Concept of Periconceptional Care

Prevention has essentially been obsessed with care which is given during the pregnancy itself, with an emphasis on encouraging women to begin care early. In fact, some obstetricians do not wish to see patients until after the second missed period, at which time embryonic development is largely completed. Some current state regulations limit the eligibility of pregnant nulliparous women for Aid to Families with Dependent Children (AFDC) to after 28 weeks gestation. Although such women may be eligible for medical assistance from the beginning of their pregnancy if they are not cohabiting, they frequently believe their eligibility for all government aid is limited to the last three months of pregnancy. Thus they do not seek care until the third trimester.

There is substantial evidence that factors relating to the mother's childhood growth and development and, perhaps, to the mother's own intrauterine existence as well, are important in pregnancy outcome (Hackman, Emanuel, van Belle, & Daling, in press). There are also other preconceptional factors relating to genetic conditions and specific predispositions which make care before conception imperative. We feel, as others, that pre-pregnancy reproductive counseling for all women would be beneficial on a population basis (British Medical Journal, 1981). For

instance, the harmful effects of smoking, alcohol use, and substance abuse on pregnancy outcome are still not universally known in the general population. Thus we will expand the definition of prenatal care to include counseling and care in the pre-, peri-, and post-conception periods.

Areas of Impact - Preconceptional and Prenatal Care

Clearly, there are certain situations where the risk for bearing a developmentally disabled child is so great that there is a body of opinion which would counsel women against pregnancy or, if pregnancy occurs, would offer the option of termination.

1. Women who chronically abuse alcohol. Chronically alcoholic women who cannot control their alcohol abuse are at very high, but at present non-quantifiable, risk for having babies with the fetal alcohol syndrome. This condition cannot be diagnosed prenatally and therefore either avoidance of pregnancy or termination appear to be prudent (Jones, Smith, Streissguth, & Myrianthopoulos, 1974).

2. Women with phenylketonuria (PKU). One of the great success stories of prevention of mental retardation has been the metabolic nutritional control of this amino acid disorder. However, present evidence indicates that women with this problem are at extremely high risk for producing retarded and malformed babies, even though the babies themselves do not have PKU (Lenke & Levy, 1980). There are no adequate studies of the mitigation of this problem by rigid control of maternal phenylalanine levels preconceptionally and throughout pregnancy, although some reviews and case reports (Lenke & Levy, 1982) suggest this possibility. These problems in babies cannot be diagnosed prenatally. Certainly, more research is necessary in this area, and there is a

widespread view among many physicians that pregnancy should be avoided or terminated in this situation. It has been hypothesized by Kirkman (1982) that a possible rebound phenomenon related to reproduction of PKU women could partially or completely wipe out the preventive benefits of the current neonatal screening and treatment programs in one generation.

3. Women with mental retardation of unknown etiology. These women are at high risk for producing retarded children, of the order of 10% for moderate or severe retardation (Lubs & Maes, 1977). Advances in diagnosis since these studies were done might remove some of the subjects from the unknown etiology category and thus alter the risk for reproduction, but in an unknown direction. Because of the risk, both biological and social, and because of questionable capabilities for child care in some cases (Schilling et al. 1981), reproductive counseling about avoidance of pregnancy and the abortion option are advocated by some professionals. In some cases where severity of retardation is combined with frequent sexual activity or the women are frequent victims of sexual abuse, sterilization may be advised by caregivers, although in some jurisdictions legal obstacles prevent this reasonable alternative (Bass, 1978).

Women who should be counseled to delay pregnancy. Teenage mothers as a group are at elevated risk for producing low birth weight babies: the younger the mother, the higher the risk (National Center for Health Statistics, 1982). This relationship also applies to VLBW babies (<1500 GM), the group at highest risk for major developmental disabilities. A number of studies have found lower IQs among the offspring of teenage mothers and have attributed this association primarily to social disadvantages (Scott, Field & Robertson, 1981).

Hardy et al. (1978) found that among black women 20-24 years of age, those who had an adolescent pregnancy had higher rates of perinatal and postneonatal deaths than those women who began reproduction after adolescence. While it is not clear whether problems of adolescent pregnancies are primarily due to biological or social factors, the fact remains that pregnant teenagers as a group are at high social risk, are more apt to be unmarried and poorly educated, and as a group have poorer pregnancy outcomes than older women (Scott et al. 1981). Even if there is no biological hazard, the multiple social and personal problems associated with teenage pregnancy indicate the need to discourage reproduction in this age group (Morris, 1981). Thus, for sexually active boys and girls, many recommend contraception and, in appropriate instances, that the abortion or adoption option should be offered.

Women who should be given preconceptional counseling and care

1. Women with Diabetes Mellitus. In spite of substantial evidence dating back several decades of the increased risk of congenital malformations in infants of diabetic mothers (IDM), only recently have studies suggested the need for prenatal detection (Milunsky, 1982). The vast majority of neural tube defects can be diagnosed prenatally and at least some cases of caudal regression syndrome are also diagnosable prenatally. Therefore pregnant diabetics should be offered sonography, and a consensus should be developed whether serum or amniotic fluid alphafetoprotein determination is more appropriate. Further, there is evidence that stricter periconceptional control of diabetes may improve outcome (Miller, 1981; Mills, Baker, & Goldman, 1979).

2. Women with history of fetal death, infant death or low birth weight baby. The evidence exists that women who have experienced a fetal death, infant death or low birth weight baby are at increased risk for a recurrence of any of these problems (Niswander & Gordon, 1972). Therefore they deserve preconceptional counseling, periconceptional and close prenatal care.

3. Women with a child with mental retardation of unknown etiology. The recurrence risk for women with one previous mentally retarded child has been estimated to be 3.7%, and for those with two previously affected children the risk is 12% (Herbst & Baird, 1982). While these conditions cannot be detected prenatally, women with such backgrounds should be apprised of these risks to help them in decisions relative to future reproduction vs. adoption.

4. Women with various chronic diseases. Besides the well-known problems of diabetic women there is evidence that women with several other chronic diseases are at risk for several problems of pregnancy outcome, some of them involving mental retardation. Women with organic heart disease had high rates of fetal mortality and low birth weight (Niswander and Gordon, 1972). Women with congenital heart disease appear to be at very high risk for producing babies with congenital heart lesions (Whittemore, Hobbins, & Engle, 1982). A number of papers show an increase in the risk of birth defects in babies of women with idiopathic epilepsy. However, several anticonvulsants, such as hydantoin, primidone and valproate, have been associated with human teratogenicity. A controversy remains as to the relative contribution of the epilepsy itself, seizures, or the anticonvulsants in producing malformations. Recent reports strongly indict valproate as being associated with neural

tube defects (Bjerkedal et al. 1982). The American College of Obstetrics and Gynecology recommends avoidance of this drug in pregnancy, especially in the first trimester (1983).

There are numerous case reports of pregnancy outcome in women with a number of rare chronic illnesses undergoing various therapeutic regimens. It is difficult because of the small numbers and the inherent biases in case reports to draw firm conclusions. We conclude that there is need for more research concerning pregnancy outcome in women with a range of different chronic diseases.

Indications for specific first trimester screening, counseling and diagnosis. There are two hundred genetic and multifactorial conditions which can be diagnosed prenatally, many of which involve mental retardation. Counseling and screening strategies vary depending on the nature of the condition (Milunsky, 1979).

1. Advanced maternal age. Reproductive counseling should be given prior to, or otherwise early in, pregnancy concerning the increasing risk for women 35 years and older bearing babies with Down syndrome and other chromosomal anomalies. Accepted community medical practice demands counseling concerning the risk and availability of prenatal detection and the termination option.

2. Groups at high risk on the basis of ethnic or other characteristics. There is a very high frequency of Tay-Sachs gene carriers (1 in 30) among Ashkenazi Jews and, in fact, several screening programs have been operating for years. Both parents are screened for the heterozygous state, and if both are positive, mid-trimester amniocentesis is performed at the parents' option (Milunsky, 1979).

3. X-linked or sex-linked disorders. Risks for such conditions are manifested by family history or by previous delivery of an affected child. Some conditions can be specifically diagnosed prenatally using biochemical tests, e.g., Lesch-Nyhan syndrome; Menkes Kinky Hair syndrome, or karyotypically, e.g., fragile-X, while in other cases a 50% risk for the fetus can be determined only by ascertainment of fetal sex, e.g., cerebral sclerosis.

4. Women with a previous child with Down syndrome or other autosomal trisomy. Such women are at increased risk for recurrence, whether the chromosomal error is trisomy, or whether a parent is a balanced translocation carrier. Thus prenatal detection and the abortion option should be offered (Milunsky, 1979).

5. Women with family history of multifactorial diseases, e.g., neural tube defects (NTD). There is general agreement that women who previously delivered NTD babies should be offered prenatal detection by sonography first, followed if necessary by amniotic fluid alphafetoprotein (AFP) determination. Women with a more distant family history should be offered maternal serum AFP determination, which, if positive, requires appropriate follow-up. There is a current debate over whether all women should be offered serum AFP screening at 16-18 weeks gestation (Oakley, 1981; Hagard, Carter & Milne, 1976). The Federal Drug Administration has recently approved the marketing of AFP test kits, which will make screening for NTDs available for all pregnant women. There is a further controversy concerning the possible role of periconceptional multivitamin or folate supplementation in preventing NTDs (Laurence et al. 1981; Owens et al. 1981; Rose et al. 1983; Smithells et al. 1983), and there is need for additional research in this regard.

In any event, women who are at high risk for having babies with multifactorial malformations should receive reproductive counseling in order to apprise them of the current state of knowledge relative to risk and prevention; this information ideally should be given before pregnancy so that the prospective parents can make decisions based on the best available knowledge. However, even if pregnancy is already established reproductive counseling is still appropriate.

Women at risk because of specific exposures.

1. Women who are exposed to chemical and physical teratogenic agents, including occupational exposures. A small number of physical and chemical agents have been established as human teratogens. Radiation during pregnancy, especially during organogenesis, was the first established teratogen, being related to microcephaly, mental retardation and growth retardation. This was confirmed by studies following the Hiroshima and Nagasaki tragedies (Miller & Blot, 1972). Thalidomide is the most notorious chemical teratogen discovered and is fortunately off the market. Because of thalidomide, there has been an obsession with the general hypothesis that most birth defects are related to extrinsic chemical agents. In spite of this widespread belief, only a small number of human chemical teratogens have been established (Kalter & Warkany, 1983a, 1983b). These include, besides the anticonvulsants mentioned above, ethanol, methylmercury, lead, coumadin, synthetic progestins, aminopterin, and iodine deficiency.

The danger of methylmercury was established by the Minimata, Japan tragedy where pregnant women ingested fish caught in industrially polluted waters (Smith & Smith, 1975). The occurrence of this cerebral palsy/mental retardation syndrome was repeated several times in other

countries, including the United States, resulting from either maternal ingestion of fungicide treated grain seed or meat fed by such treated seed (Synder, 1971).

The most notorious environmental/occupational exposures alleged to detrimentally influence pregnancy outcome are the phenoxy acid herbicides, agent orange and its constituents. Nevertheless there is no good evidence at this time to incriminiate these substances in human teratogenesis (Smith et al. 1982; Kunstadter, 1982), but work continues.

There is more evidence, however, related to waste anesthetic gases, although the data are rather inconsistent (Kalter & Warkany, 1983a, 1983b). In addition to possible teratogenesis related to anesthetic gases, such occupations as physicians, nurses, dentists and dental hygienists are also exposed to infectious agents and radiation. Reproductive risks for these occupations, both for females and males, are poorly studied and there is no general agreement relative to periconceptional counseling.

While there has been a rapid increase over recent decades in both the number and quantities of chemicals to which populations in industrial countries are exposed, the Centers for Disease Control reported in 1982 that there is no evidence from several malformation monitoring systems of unexplained increased teratogenesis, with a possible exception of ventricular septal defect. In fact, neural tube defects have been on the decrease in many countries for which secular trend data are available (Elwood & Elwood, 1980). Kalter and Warkany (1983a, 1983b) have presented evidence that maternal exposure to lead causes mental retardation in offspring. In any event, it is extremely difficult to study the possible effect of any potential morphologic or behavioral

teratogens. Therefore periconceptional care should include advice about avoidance of all toxic substances and non-essential medicines.

2. Substance abuse. Using the broad definition of teratogenesis, cigarette smoking during pregnancy is a teratogen since it is causally related to low birth weight, miscarriage, perinatal mortality and minor long-term deficits in postnatal growth and development (Landesman-Dwyer & Emanuel, 1979). It has been estimated that smoking is the single most prevalent preventable cause of low birth weight in this country. Opiates are associated with low birth weight, withdrawal symptoms and possible long-term behavioral abnormalities (Wilson et al. 1973). The most important abused substance related to frank mental retardation in offspring is ethanol. Since it is not known whether there is a truly safe level of alcohol intake during pregnancy, efforts should be made to discourage drinking during the entire pregnancy (Council on Scientific Affairs, 1983). While birth defects are the major concern related to maternal ingestion of medicines and non-therapeutic drugs, clearly more attention must be paid to possible behavioral teratogenesis, particularly since many of these substances act on the central nervous system.

3. Infections. Congenital rubella is essentially completely preventable by vaccination, which should occur by the age of menarche. Determination of rubella immune status should be a routine aspect of the first prenatal visit. Care of pregnant susceptibles involves the following: (a) they should be counseled to avoid exposure, (b) if exposure or a rash disease occurs, appropriate serologic tests should be obtained and, if positive, counseling should be given concerning risk and the termination option, and (c) those who still are susceptible at pregnancy's end should be vaccinated following delivery.

Neonatal herpes infection is devastating both with respect to mortality and severe mental retardation (Jenista, 1983). Since caesarian section will almost always prevent newborn disease, many advocate cultures at term for women with a history of disease in order to diagnose recurrences which would necessitate operative delivery.

Other sexually transmitted diseases also carry risks for the newborn. A recent study showed a resurgence of congenital syphilis in babies of women with inadequate prenatal care (Mascola, 1983). Serologies should be obtained at first visit and treatment given if necessary. The current epidemic of gonorrhea demands constant vigilance towards maternal diagnosis and treatment and newborn ophthalmic prophylaxis. There is some evidence that genital chlamydia infections are associated with prematurity and perinatal mortality (Martin et al. 1983) and some therefore advocate treatment of high risk groups if positive.

As diagnosis of toxoplasmosis in adults is so difficult, prudent avoidance of possible exposures should be recommended. This includes avoidance of cats and undercooked meat.

Intrauterine cytomegalovirus infection is undoubtedly a major cause of mental retardation. Because the infection, both primary and recurrent, is usually silent or non-specific in adults, diagnosis is difficult. Further, serological and virological testing is almost entirely a research endeavor. Clearly this is a problem which demands considerable research emphasis.

Women with active tuberculosis are at risk for having babies with congenital infection or infants who develop postnatal infection, both predisposing to tuberulous meningitis (Good et al. 1981). Therefore,

high risk women such as refugees from developing countries should be screened for this problem.

Monitoring the Progress of Pregnancy via Prenatal Care

Discussion so far has related to specific categories of women or to specific environmental risk factors. In addition to these concerns there are certain procedures and considerations applicable to all women. The establishment of an accurate gestational duration is of primary importance for several reasons: (a) as a baseline for monitoring fetal growth, (b) for early determination of Rh, rubella and syphillis immune status, (c) for planning second trimester prenatal detection procedures for eligible women, and (d) for planning optimal treatment in the event of premature labor or post-term pregnancy. Traditionally, gestational duration has been determined by date of last menstrual period and by such clinical means as uterine size, quickening and auscultation of fetal heart tones. All of these have inherent inaccuracies and, more and more, clinicians are relying on sonography in the first two trimesters. Sonography has the added advantages of early detection of multiple gestations and a number of congenital malformations.

Women who had previous poor outcomes, such as prematurity, low birth weight, intrauterine growth retardation and perinatal death need to be monitored closely, since they are at risk for recurrence of one or the other of these problems. A number of obstetrical investigators advocate special intensive prenatal care clinics for these women, including education of patients to identify early signs of labor for possible tocolytic therapy (Herron, Katz, & Creasy, 1982).

There are a number of scoring systems to separate women into low and high risk groups, none of which is sufficiently sensitive or specific.

For instance, about one quarter of a group of low risk women, carefully selected for alternative birthing care and delivery, needed to be transferred to standard obstetric care before or during labor (Falson et al. 1979). Clearly more work needs to be done to better identify risk of problem outcomes.

Nutritional intake and supplementation studies have been variable and controversial. One of the best controlled supplementation studies has found that high protein intake was related to prematurity, growth retardation and neonatal death. Given the present state of knowledge, maintenance of a well-balanced diet commensurate with adequate weight gain is to be strived for (Rush, 1982).

Maternal nutritional status must be important in outcome. Prepregnancy weight is considered an important predictor of baby's birth weight, yet the correlation coefficient is only about 0.25 for both blacks and whites (Garn & Pesick, 1982). Pregnancy weight gain is also considered a valuable monitoring variable, yet its correlation with baby's birth weight is of the order of 0.3, and the correlation coefficient of birth weight with gestational duration is about twice that magnitude (Hackman & Emanuel, unpublished). Obviously there are many still unknown factors in pregnancy outcome.

Pregnancy-induced hypertension (toxemia) is a major cause of both fetal and maternal morbidity. Its possible occurrence must be monitored and the delivery time based on perceivable hazards to either the mother or baby.

Conclusions and Recommendations

Recently this country and other industrial countries have seen dramatic improvements in infant mortality rates. This has been

attributed primarily to improvement in obstetric and neonatal intensive care, particularly with respect to premature and low birth weight babies (Lee et al. 1980). The fact remains that these problems occur excessively among the lower socioeconomic groups in all countries studied. The strategy for the future should concentrate more on primary prevention rather than expensive, complicated and as yet inadequate treatment of problems. Quite clearly, causes of poor pregnancy outcome, including many conditions involving mental retardation and other developmental disabilities, are poorly understood and demand intensive investigation if primary prevention is to be achieved.

There is increasing evidence that preconceptional or so-called intergenerational factors are of importance in some problems of pregnancy outcome. A longitudinal study has found that women tend to produce babies with similar birth weight and gestational duration characteristics irrespective of age, parity or problems of pregnancy and delivery (Bakketeig, Hoffman & Harley, 1979). A recent study shows that maternal birth weight is related to later reproductive performance including the following: birth weight, gestational duration, relative intrauterine growth, and certain perinatal problems of their babies (Hackman et al. in press). British and other studies provide substantial indirect evidence that conditions to which mothers have been exposed during their own childhoods impact on their reproductive performance (Baird, 1980).

Since intensive investigations over the years with respect to the pregnancy and perinatal periods have not resulted in anything approaching adequate understanding of the causes of abnormal reproductive outcome, it would appear worthwhile to look more closely at possible preconceptional factors, admittedly a more difficult task. It has been proposed that at

least some problems of pregnancy outcome are related to three categories of factors: genetic; intergenerational or preconceptional, pertaining to the period before pregnancy ensues; and immediate, pertaining to the pregnancy in question (Emanuel and Sever, 1973). This conceptual scheme might form the basis for future investigations of a number of problems. Put another way, healthy babies become healthy children who grow up to be healthy adults who become healthy parents who produce healthy babies. A recent review by Enkin & Chalmers (1982) of the historic and scientific bases for contemporary prenatal care points out that adequate clinical trials have not been conducted for many accepted practices and thus calls them into question. The volume points to the need to ascertain the effectiveness of many accepted but unproven prenatal care practices. There is also an appropriate emphasis for the place of empathy, warmth, and kindness as important features of care of women during pregnancy, which is one of the most important and urgent periods of a woman's life.

Linkages Between UAFs and Other Title V Programs - Means to Improve Periconceptional Care.

It is clear that a variety of federal and state supported Title V programs are involved in prenatal care in an effort to improve pregnancy outcome in general and, specifically, to prevent mental retardation. The Maternal and Infant (M & I) Care Program was specifically established to prevent mental retardation in medically indigent groups. While its effectiveness in this regard has never been adequately studied, there is evidence that M&I programs, properly managed, can improve pregnancy outcome (Sokol et al. 1980). The question of variability in the content of care in M&I programs needs to be addressed and the content of effective programs replicated. The same can be said for the Improved Pregnancy Outcome Programs (IPOP).

There is now substantial evidence that Regional Perinatal Programs have been instrumental in reducing infant mortality, particularly among very low birth weight babies (VLBW), and there is evidence that the prevalence of major handicaps in VLBW survivors has seen a rapid secular decrease (Stewart et al. 1981), probably related to obstetric and neonatal intensive care. Because the Regional Perinatal Programs have been responsible for developing referral systems for high risk deliveries, they may be responsible for some reduction in handicap prevalence.

Some Adolescent Health Programs are involved in prevention of teenage pregnancy and in the care of pregnant teenagers and their children. Some UAFs are also involved in such activities. Pediatric Pulmonary Training Programs, in addition to training, provide services to infants and children with respiratory problems and thereby may help reduce the chronicity of, and disability related to, such problems. Lastly, state genetics programs, by providing counseling, intrauterine and postnatal diagnosis, and neonatal screening, very specifically have a real role in preventing mental retardation.

Some MCH supported UAFs are involved in one or all of these federally and state supported Title V programs. A real need, which is not fully met by UAFs or other organizations is the follow-up of all infants who required treatment at Regional Perinatal Centers and other neonatal intensive care units. Financial constraints prevent fulfillment of this need. Some UAFs are heavily involved with State Genetics Programs in several ways, including assuring that babies with metabolic defects receive optimum care to prevent mental retardation. A crucial emerging problem in which UAFs can and should play a major role is the follow-up

into adulthood of children with PKU, so that affected women are made aware of their extremely high risk for poor pregnancy outcome. A nationwide surveillance and care system should be established for PKU women to offer the following: reproductive counseling, including risk assessment; advice concerning the adoption option; abortion counseling in the event of inadvertent pregnancy; periconceptional and prenatal metabolic control and optimal prenatal care if pregnancy is desired; and intensive follow-up of infants. In such systems, the latest information concerning risk and prevention can be conveyed to the women as it is developed.

M&I and IPOP patients are frequently referred to Regional Perinatal Centers and UAFs can play a role in caring for some of these women and their infants. UAFs can work with Adolescent Health Programs and with state and local MCH agencies in attempting to reduce the epidemic of teenage pregnancy and in improving outcome of these pregnancies.

There are currently eight Schools of Public Health which have maternal and child health programs supported by DMCH. The purpose of these programs is to train professional personnel for leadership roles in the MCH field. It would appear to be of mutual advantage for such programs to develop relationships with UAFs for the purpose of joint training and collaborative research directed toward prevention of handicapping conditions and the improvement of care of handicapped children.

Many of the possible linkages between UAFs and other MCH programs have been established, but the linkage process has not been completed and, to a large extent, financial restraints prevent its full expression. The effectiveness of linkages, once established, needs to be

studied, so that optimum content of care for the prevention of abnormal pregnancy outcome, including mental retardation and other developmental disabilities, can be determined and replicated. Lastly, linkages will always depend on goodwill and a spirit of cooperation and mutual aid among the personnel in the agencies involved and on a concern for the people they are charged to help.

References

American College of Obstetrics and Gynecology. Newsletter, January 1983.

Baird, D. Environment and reproduction. British Journal of Obstetrics and Gynaecology, 87, 1980, 1057-1067.

Bakketeig, L.S., Hoffman, J.H. & Harley, E.E. The tendency to repeat gestational age and birth weight in successive births. American Journal of Obstetrics and Gynecology, 135, 1979, 1086-1103.

Bass, M.S. Surgical contraception: A key to normalization and prevention. Mental Retardation, December 1978, 399-403.

Bjerkedal, T., et al. Valproic acid and spina bifida. Lancet, November 13, 1982, 1096.

British Medical Journal, Editorial, 238, 1981, 685.

Broman, S.H., Nichols, P.L. & Kennedy, W.A. Preschool IQ - Prenatal and Early Developmental Correlates. Hillsdale, N.J.: Lawrence Erlbaum Associates, 1975.

Centers for Disease Control: Congenital Malformations Surveillance Report, January-December 1980, Issued February 1982.

Council on Scientific Affairs. Fetal effects of maternal alcohol use. Journal of the American Medical Association, 249, 1983, 2517-2521.

Elwood, J.M. & Elwood, J.H. Epidemiology of Anencephalus and Spina Bifida, New York: Oxford University Press, 1980.

Emanuel, I. Problems of outcome of pregnancy: Some clues from the epidemiologic similarities and differences. In Kelly, S., Hook, E.B., Janerich, D.T., and Porter, I.H., eds., Birth Defects, Risks and Consequences. New York: Academic Press, 1976.

Emanuel, I. & Sever, L.E. Questions concerning the possible association of potatoes and neural-tube defects, and an alternative hypothesis relating to maternal growth and developmental. Teratology, 8, 1973, 325-332.

Enkin, M. & Chalmers, I. Effectiveness and satisfaction in antenatal care. In Enkin, M., and Chalmers, I., eds., Effectiveness and Satisfaction in Antenatal Care. Philadelphia: J.B. Lippincott Co., 1982.

Falson, J.B., et al. The childbearing center: An alternative birth setting. Obstetrics and Gynecology, 54, 1979, 527-532.

Garn, S.M. & Pesick, S.D. Relationship between various maternal body mass measures and size of the newborn. American Journal of Clinical Nutrition, 36, 1982, 664-668.

Good, J.T., et al. Tuberculosis in association with pregnancy. American Journal of Obstetrics and Gynecology, 140, 1981, 492-498.

Hackman, E. & Emanuel, I. Unpublished data.

Hackman, E., Emanuel, I., van Belle, G., & Daling, J. Maternal birth weight and subsequent pregnancy outcome. Journal of the American Medical Association, in press.

Hagard, S., Carter, F., and Milne, R.G. Screening for spina bifida cystica. British Journal of Preventive and Social Medicine, 30, 40-53, 1976, 40-53.

Hardy, J.B., et al. Long-range outcome of adolescent pregnancy. Clinical Obstetrics and Gynecology, 21, 1978, 1215-1232.

Herbst, D.S. & Baird, P.A. Sib risks for nonspecific mental retardation in British Columbia. American Journal of Medical Genetics, 13, 1982, pp. 197-208.

Herron, M.A., Katz, M. & Creasy, R.K. Evaluation of a preterm birth prevention program: Preliminary report. Obstetrics and Gynecology, 59, 1982, 452-456.

Janista, J.A. Perinatal herpesvirus infections. Seminars in Perinatology, 7, 1983, 9-15.

Jones, K., Smith, D.W., Streissguth, A. & Myrianthopoulos, N. Outcome in offspring of chronic alcoholic women. Lancet, June 1, 1974, 1076-1078.

Kalter, H. & Warkany, J. Congenital malformations (1). Etiologic factors and their role in prevention. New England Journal of Medicine, 1983, 424-431.

Kalter, H. & Warkany, J. Congenital malformations (2). New England Journal of Medicine, 308, 1983, 491-497.

Kunstadter, P. A study of Herbicides and Birth Defects in the Republic of Vietnam. National Academy Press, National Academy of Sciences, 1982.

Kirkman, H.N. Projections of a rebound in frequency of mental retardation from phenylketonuria. Applied Research in Mental Retardation, 3, 1982, 319-328.

Landesman-Dwyer, S. & Emanuel, I. Smoking during pregnancy. Teratology, 19, 1979, 119-125.

Laurence, K.M., et al. Double-blind randomised controlled trial of folate treatment before conception to prevent recurrence of neural-tube defects. British Medical Journal, 282, 1981, 1509-1511.

Lee, K-S., et al. Neonatal mortality: An analysis of the recent improvement in the United States. American Journal of Public Health, 70, 1980, 15-21.

Lenke, R.R. & Levy, H.L. Maternal phenylketonuria and hyperphenzlalanemia. An international survey of the outcome of untreated and treated pregnancies. New England Journal of Medicine, 303, 1980, 1202-1208.

Lenke, R.R. & Levy, H.L. Maternal phenylketonuria - Results of dietary therapy. American Journal of Obstetrics and Gynecology, 142, 1982, 548-553.

Lubs, M.-L.E. & Maes, J.A. Recurrence risk in mental retardation. In Mittler, P., Ed., Research to Practice in Mental Retardation, Vol. III Biomedical Aspects. Baltimore, Md.: University Park Press, 1977.

Martin, D.H. et al. Prematurity and perinatal mortality in pregnancies complicated by antepartum maternal Chlamydia trachomatis infections. Journal of the American Medical Association, 247, 1982, 1585-1588.

Mascola, L. Congenital syphilis in the US-1980. Presentation at Epidemic Intelligence Service 32nd Annual Conference, Centers for Disease Control, Atlanta, 1983.

Miller, E., et al. Elevated maternal hemoglobin A_{1c} in early pregnancy and major congenital anomalies in infants of diabetic mothers. New England Journal of Medicine, 304, 1981, 1331-1334.

Miller, R.R. & Blot, W.J. Small head size after in utero exposure to atomic radiation. Lancet, 2, 1972, 784-787.

Mills, T.L., Baker, L. & Goldman, A.S. Malformations in infants of diabetic mothers occur before the seventh gestational week: Implications for treatment. Diabetes, 28, 1979, 292.

Milunsky, A., ed. Genetic Disorders and the Fetus. Diagnosis, Prevention and Treatment. New York: Plenum Press, 1979.

Milunsky, A., et al. Prenatal diagnosis of neural tube defects, VIII. The importance of serum alpha-fetoprotein screening in diabetic pregnancy women. American Journal of Obstetrics and Gynecology, 142, 1982, 1030-1032.

Morris, N.M. The biological advantages and social disadvantages of teenage pregnancy. American Journal of Public Health, 71, 1981, 796.

National Center for Health Statistics: Advance report of final natality statistics, 1980. Monthly Vital Statistics Report, Vol. 31, No. 8 Supp. DHHS Pub. No. (PHS)83-1120, November, 1982.

Niswander, K.R. & Gordon, M. The Women and Their Pregnancies. DHEW Publication No. (NIH) 73, 1972, 379.

Oakley, G.P., Jr. Antenatal Diagnosis: Potential for major reduction in pediatric morbidity. Pediatric Annals, 10, 1981, 13-21.

Owens, J.R., et al. 19-Year incidence of neural tube defects in area under constant surveillance. Lancet, November 7, 1981, 1032-1035.

Querec, L.J. Apgar Score in the United States, 1978. Monthly Vital Statistics Report, U.S. Dept. of Health and Human Services, 30, Supp., May 6, 1981, 1.

Rose, G., et al. Vitamin supplementation for prevention of neural tube defect recurrences. Lancet, May 21, 1983, 1164-1165.

Rush, D. Effects of changes in protein and calorie intake during pregnancy on the growth of the human fetus. In Enkin, M. & Chalmers, I., eds., Effectiveness and Satisfaction in Antenatal Care. Philadelphia: J.B. Lippincott Co., 1982.

Scott, K.G., Field, T. & Robertson, E.G., eds. Teenage Parents and Their Offspring. New York: Grune and Stratton, 1981.

Schilling, R.F., et al. Child maltreatment and mentally retarded parents: Is there a relationship? Mental Retardation, 20, 1982, 201-209.

Smith, A.H., et al. Congenital defects and miscarriages among New Zealand 2,4,5-T sprayers. Archives of Environmental Health, 37, 1982, 197-200.

Smith, W.E. & Smith, A.M. Minamata. New York: Holt, Rinehart and Winston, 1975.

Smithells, R.W., et al. Further experience of vitamin supplementation for prevention of neural tube defect recurrences. Lancet, May 7, 1983, 1027-1031.

Snyder, R.D. Congenital mercury poisoning. New England Journal of Medicine, 284, 1971, 1014-1016.

Sokol, R.J., Woolf, R.B., Rosen, M.G., Weingarden, K. Risk, antepartum care, and outcome: Impact of a maternity and infant care project. Obstetrics and Gynecology, 56, 1980, 150-156.

Stanley, F. Medical care of the fetus and the risk of prematurity. In Reed, D., and Stanley, F., eds., Epidemiology of Prematurity. Baltimore: Schwarzenberg, 1977, 269-279.

Stanley, F.J. An epidemiological study of cerebral palsy in Western Australia, 1956-1975. I: Changes in total incidence of cerebral palsy and associated factors. Developmental Medicine and Child Neurology, 21, 1979, 701-713.

Stewart, A., Reynolds, E. and Lipscomb, A. Outcome for infants of very low birthweight: Survey of world literature. Lancet, May 9, 1981, 1038-1041.

Taffel, S. Prenatal care in the United States, 1969-1975. Vital and Health Statistics, U.S. Dept. of Health, Education, and Welfare, Series 21-Number 33, DHEW Publication No. (PHS) 78-1911, September 1978.

Whittemore, R. Hobbins, J.C. & Engle, M.A. Pregnancy and its outcome in women with and without surgical treatment of congenital heart disease. American Journal of Cardiology, 50, 1982, 641-651.

Wilson, G.S., et al. Early development of infants of heroin-addicted mothers. American Journal of Diseases of Children, 126, 1973, 457-462.

Wilson, J.G. Environment and Birth Defects. New York: Academic Press, 1973.

HUMAN COST OF CHRONIC ILLNESS

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Children with chronic illness and their families require a set of services substantially different than those required by the majority of the nation's children. Just as there is no escaping the presence of a chronic illness for a child and family, the health care system can not escape its responsibility to provide these services.

The needs of these children and families are made urgent by the extraordinary success of medical technology. Advances in the diagnostic and medical treatment procedures for numerous chronic illnesses have been remarkable, allowing many children to live far longer and in much better health than anyone would have expected two decades ago but the nation has not been as attentive to other services. A child with diabetes may have the finest medical care available in the region; yet, the family may lack the money for gas to visit the child in the hospital. The cystic fibrosis specialist may develop a comprehensive management strategy for the patient, but it fails to have full effect because the family's local pediatrician remains uninformed. These and many other examples convince us that the first step towards improving services to these children and their families must involve sustained national attention to their broad and special needs.

To highlight these needs we present a story told from the

perspective of a father of a child with spinal bifida.

When I look back on it all, I wonder how I could have been so unprepared. The obstetricians and specialists were very reassuring. Spina bifida, they said, was serious and the medical treatments were complicated, but the necessary technology was available; my son, John Jr., would live and "probably attain a reasonable level of functioning," they said. They were right on both counts. John is now nine and as smart as anyone his age.

In the first week after birth, I tried to track down as much information as I could about spina bifida. It wasn't easy; my town of 100,000 didn't have large libraries or good bookstores. I found some material, but in retrospect, I see how little I really had understood about spina bifida and what it would mean to my family.

Part of the problem, I've realized, was that the docs often didn't know themselves how John Jr. would respond after a particular operation. But, for some reason, instead of admitting that they didn't know, they were almost always reassuring. I am certain that the docs were trying to be helpful, but they came across as condescending. When it came to knowing what to do, I felt so impotent but their reluctance or inability to explain what was happening in a way that we could understand made it even worse. Eventually when John Jr. was two years old we finally found a pediatrician in a nearby town who was very helpful; most importantly, he spent some time with us. For that alone we were very grateful. He kept asking not only how John Jr. was doing, but also how we were doing. Often he suggested taking a weekend away, wise advice that we didn't follow.

It seemed to me that when we weren't worrying about John Jr., we were worrying about money. I was a Presbyterian minister then and my wife had just finished social work school. Not poor, but we sure got that way fast. My insurance wasn't great. The inpatient bills were mostly covered, and CCS chipped in some. It was the outpatient bills and all the extras that really hurt us: gas money, phone bills, a special bed, home nurses (until we ran out of money for them). After six months, worrying about money became a habit.

It wasn't only the money problem that finally got to me; the many contradictions in the medical system did also. When John Jr. was three I wanted to take him to the beach and take him in the water. So I asked the docs if they thought that would be OK. The neurosurgeon said "yes"; the urologist said "no"; and the orthopedist said "maybe". The social worker said "Well, I'm not sure. Let me ask the docs." I finally listened to our pediatrician who said, "Just go have fun and use your own judgment." He turned out to be right.

We saw that there were very practical things that could have been changed to make life less difficult for us. For example, we soon realized that different clinics operated on different days--a

fine arrangement for the docs, the nurses, secretaries, and most kids. It wasn't fine for John Jr. or my wife or me. Over and over we wished we could go to the hospital and get everything done at once. I remember that we had a running joke about the four secretaries in the different clinics. We would say "If it's Gwinn, it must be Wednesday."

Finally, though, there wasn't any more room for humor. After John Jr. was three and after about six months of no operations and no problems, he started having recurrent urinary tract infections. My wife and I couldn't seem to manage it well enough and we would get mad, and begin blaming the other one for the recurrent crises that led to such pain for John Jr. and to more hospitalizations. I guess all that anger that we had been storing up finally came out.

I know that we made it worse for everyone, but the docs and the nurses could have been more understanding. It wasn't that I wanted them to listen to my emotional problems--I knew they didn't have time for that. But they seemed so reluctant simply to recognize our feelings, or even their own. Everyone was so controlled and objective, as if being emotional was going to interfere with treatment. At one point, we began talking to a psychologist who worked with the various clinics at the hospital. In retrospect a lot could have been avoided if we had talked with her right from the start instead of waiting until a crisis. But even she couldn't help us with everything.

This was true for John Jr. also. His feelings often came out in a rush, after months of seeming indifference. "Stupid doctor," he said once, with a bitterness I had not heard before. "It took him eight sticks to get the IV in. My arm hurts bad. He didn't evey say sorry. Why can't they at least say they're sorry?" And then he started to cry.

At one point, when John was five, just after hospitalization, I overheard him say, "Mommy, am I going to die?" In a peculiar voice my wife said "Oh no, of course not; not any time soon." I don't think this was the best answer, but I'm not sure I would have done any better if I had been on the spot. We should have anticipated these sorts of questions and sat down to plan how we would respond.

When the urinary infections finally stablized, John Jr. was almost five and my marriage was almost over. The strain had been too much for my wife and she finally announced that she was leaving the marriage, taking our older daughter (Carolyn) and leaving John Jr. to my care. She said that she would do as much as she could but she couldn't live with him anymore. I don't really blame her. She spent those five years foreclosing on all her dreams of a career. And Carolyn, she was often overlooked in all of this, but that's another story.

I've gottn out of the ministry now. I couldn't care for my child and my congregation at the same time and the salary and

health insurance just weren't enough. I've moved to a large city, and gotten a job in public relations. I belong to an HMO, and I'm trying to help them start a special package for a limited number of chronically ill children; John Jr. could get all the services he needs under one roof but so far they won't take him because they are afraid he's going to cost too much money. Right now most of John's medical care is supported by CCS.

The big lesson I've learned is that the medical community seems reluctant to take responsibility for the implications of their success. They got us through the birth and all the medical crises wonderfully. But then they seemed so unwilling or unable to help us with everything that came after. Perhaps they, like me, are unprepared to know what childhood chronic illness truly means.

This story illustrates with some specifics the general needs of chronically ill children and their families. It points to the importance of promoting an adequate quality of life for the child and the family, improving the organization of service, and developing sufficient financing of services.

Aiding the Family in Raising a Chronically Ill Child

In planning service programs for chronically ill children and their families, there are a number of issues which confront these families regardless of the specific condition of the child.

- The daily burden of care is often extremely stressful;
- The course of the disease may be highly unpredictable and the fact of chronicity creates special problems of coping for the family and child;
- Treatment regimes are often complex and sometimes conflicting;
- The treatment itself may be arduous, painful and sometimes embarrassing;
- Some chronic childhood illnessess are accompanied by extreme pain and discomfort;
- For the parents, fatigue, marital stress, low family morale,

reduced career mobility, and poor adjustment of siblings are recurring problems;

- For the child, diminished school performance and social adjustment may be the result of frequent absences, low energy, and need for health care while in school;
- With respect to the future, there is uncertainty regarding education and vocation.

Major reactions a family may have to a child with chronic illness include:

- Parental disappointment, shame, or guilt;
- Parental resentment or anger over the burden;
- Parental anxiety leading to overprotectiveness, overrestrictiveness, over-indulgent care;
- Overconcentration of attention on the sick child, resulting in underattention to needs of other family members, fatigue, depression, and family impoverishment;
- Distortion of family life with respect to where to live and what to do;
- Sibling resentment of the patient as the recipient of special and favored attention and also shame caused by having an abnormal sibling;
- Sibling vulnerability with respect to parental transference of overprotective attitudes and practices to them and, if the patient dies, grief and depression in anticipation of outcome. (Talbot & Howell, 1971)

The nature of different illnesses will create varying degrees of financial burden on the family such as the cost of blood plasma in

hemophilia; housing adaptations such as those needed for spina bifida and muscular dystrophy; physical demands such as lifting, dressing, feeding, and extra house cleaning with illness such as cystic fibrosis, asthma, spinal cord damage; and disruption in family routines such as sleep interruptions with children who have asthma and special dietary planning for children with renal disease and diabetes. Regardless of specific burdens, the illness will challenge the family's ability to cope with the needs of the affected child.

Furthermore, depending upon the age of the chronically ill child, these family reactions and disease characteristics will have varying consequences. Unfortunately, the overall impact of a chronically ill child on a family system is usually more disintegrative than integrative, disrupting the lives of all the family members and exacerbating the developmental risks to the child.

The structure of the family, the parameters of the illness, and the developmental needs of the child all interact to determine effective coping of the child and family. The ability of the family to respond to the emotional and the physical needs of the chronically ill child is determined in large part by the level of stress and the family's ability to manage that stress. The existing relationships within the family, its stability, and its broad community network of support will all affect the family's response to this stress and consequently their role in the socialization process of the chronically ill child.

For any child, development is, by and large, an orderly, sequential, cumulative process that leads to increased skill and mastery of the environment. Nonetheless, at each stage of development, the child is vulnerable to external stress that interacts with the

developmental process. When a chronic illness superimposes on the developmental process, it may compromise the ongoing emergence of new skills and the solidification of recent developmental gains - both psychosocial and cognitive (Magrab & Colcagno, 1978). Mastering the frustrations and disappointments normally occurring in the various developmental periods is dependent upon the expectation and hope of the child that he/she will be older, stronger, and better able to solve problems (Stubblefield, 1974). When a chronic illness casts doubt on these expectations, the course of development may be significantly disrupted.

For a child with a chronic illness, a number of basic emotional needs are challenged: (1) love and affection, (2) security, (3) acceptance as individual, (4) self-respect, (5) achievement, (6) recognition, (7) independence and, (8) authority and discipline (Hughes, 1976). Each of these take on a special meaning at the various stages of development of the child and with respect to the special features of the existing medical condition. Restrictions in daily activities, interpersonal communications, education, and plans for career and marriage are concrete features of particular illnesses that have major effects on the developmental process.

The family and child need information and support to cope effectively with the various stresses of a chronic illness. Providing support to all members of the family, including siblings, and assisting families in networking with the extended family, neighbors, friends and parent groups are important components in overall health care management. Anticipatory guidance in terms of what to expect with the chronicity of the disease is another important component of

comprehensive care.

The quality and availability of comprehensive health, social and educational services will have a potent impact. The fragmentation of services and the lack of coordinated care for this group of children continues to be a significant problem. Developing a system where there is continuity of care throughout the life cycle of these individuals has not been achieved. Rarely are developmental issues adequately considered in either individual treatment planning or the development of large scale service programs. Health care planners must become sensitive to the interaction between chronic illness and developmental needs.

Professionals working together recognize that no single profession has the capability of providing all the needed services to a chronically ill child and the family. A number of professionals must share in both medical and psychological management. Through integrated team care, various mental health professionals including social workers, psychologists, psychiatrists, and nurses can, in various ways, help the team respond effectively to the psychosocial aspects of the child's condition and to the needs of the family.

Professionals must learn to share in the responsibility for aiding both the child's and the family's adjustment to the chronic illness. The roles of the professionals will vary depending on the resources in a given community, but services are best delivered when there is a team approach to providing comprehensive care. The team approach not only provides better care but also offers the professional a support mechanism for performing a very stressful job. At times, feelings of helplessness on the part of the professional can create distancing from

the patient and the family. Through team support, professionals can better face their own vulnerabilities and the child and the family can receive more optimum care.

Implications for Title V Programs and UAFs

Title V Programs, in assuming the responsibility for handicapped and chronically ill children, must continue to foster the utilization of a team approach, emphasizing the broad spectrum of needs of the family and the child. Fragmentation of services is perhaps one of the most frustrating aspects of caring for a chronically ill child. At both the state and local level, the Title V agency can be an advocate for developing coordinated and regionalized systems of care.

Children are best served within their community to the extent that this is possible. Maternal and Child Health and Crippled Children's (MCH/CC) agencies can assist communities in developing local resources for care as part of a regionalized system. Clearly tertiary care services will be required by most chronically ill children but many of the services currently available in tertiary settings could be identified in a local community through creative organizations of service delivery and inservice training of personnel. There are several existing exemplary models of community based care: Rural Effort to Assist Children at Home in Central Florida (Project REACH) that prepares nurses to provide home care for chronically ill and medically dependent children who live in their communities; the Pediatric Home Care Program at Albert Einstein College of Medicine, New York, in which teams of pediatric nurse practitioners, social workers and pediatricians make home visits to families of chronically ill children who live in the south Bronx, the Home Care Team at Children's

Hospital National Medical Center, Washington, D.C., that insures, through teams of nurses, social workers, educational specialists and physicial therapists that medically dependent infants and children are adequately transferred from the hospital and maintain appropriately at home; and the project sponsored by the Association for Care of Children's Health (ACCH) on Community Networking for Improved Services to Children with Chronic Illnesses (Ireys, 1983).

The MCH/CC agency at the state level is in a position to encourage community collaboration and to develop and formalize systems of regionalized care. Because of its long involvement with chronically ill children, it is in the position to take a leadership role within the state for developing comprehensive services for all children with chronic illness, serving as a systems builder on behalf of all children with chronic illness and their families.

As services to chronically ill children become more community based, there will be an increasing need for inservice training to professionals who will provide this care. University Affiliated Facilities (UAFs) have had a vast experience in developing training models for the care of handicapped children which have a direct correlation to the kinds of services needed for the chronically ill child. A UAF can provide a natural arena for training in the team approach, the management of family and child adjustment issues and, in some instances, the development of coordination of service systems. They represent a logical training vehicle that has a well established network for dissemination.

In particular, in working with handicapped children, UAFs have been able to transcend categorical interests in specific handicaps and

develop more generic training programs. This has an important implication for training development with respect to chronic illness. With these children there are often more within-group differences than between-group differences. Professionals can be trained and prepared to work with a broad category of chronically ill children in providing support services to the child and the family. UAFs are in an excellent position to develop inservice training packages to this end.

In terms of developing regionalized systems of care and community coordinated services, UAFs have been active in the development of such systems for the handicapped child. Building on that work, UAFs are in a position to assist in the further development of innovative community models; to disseminate such models, i.e., home care; and to train professionals to provide appropriate services.

Because of their long involvement with handicapped childen and the many similar issues in the care of chronically ill children, UAFs represent an important resource for the development of community based team care. There is a national partnership forseeable between MCH/CC agencies and UAFs in this development of new models and training networks on behalf of chronically ill children and their families.

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References

Hughes, J. The emotional impact of chronic disease: The pediatrician's responsibility. American Journal of Diseases of Children, 130, 1976, 1200-1203.

Ireys, Henry, Guest Editor. Children's Health Care, 12 (2), In press, Fall, 1983.

Magrab, P.R. & Calcagno, P.L. Psychological impact of chronic pediatric conditions. In P. Magrab (ed.) Psychological Management of Pediatric Problems: Early Life Conditions and Chronic Disease. Baltimore: University Park Press, 1978.

Stubblefield, R. Psychiatric complications of chronic illness in children. In J.A. Downey & N.L. Low (eds.) The Child with Disabling Illness. Philadelphia: W.B. Saunders Co., 1974.

Talbot, N.B. & Howell, M.C. Social and behavioral causes and consequences of disease among children. In N.B. Talbot, J. Kagan, & L. Eisenberg (eds.), Behavioral Science in Pediatric Medicine. Philadelphia: W.B. Saunders Co., 1971.

II.
A CONSIDERATION OF LINKAGES

The concerns of UAF service programs and curricula overlap substantially with the principal areas of assignment of other Title V project activities, especially within state health departments. Services for handicapped children, genetic disease detection and counseling, supports to adolescent individuals, follow-up of infants at risk, prevention of handicap by services for pregnant women and troubled newborns, screening programs, and improved understanding of the causation of developmental disorders are, for example, all territories of common interest and involvement. Hence, it is not surprising that mutual resolves leading to mutual activities, have occurred in many settings between UAFs and MCH/CC programs. For the purposes of the present report these are referred to as "linkages." An analysis of such partnerships follows.

Table 1 summarizes components of alliance in 18 UAFs, with an attempt to capture the leading features involved in training, service, advisory functions, shared staff, technical assistance, planning, and research. The degree of involvement in each instance is reflected by assigning a weight according to the key provided with the chart.

It is perhaps inevitable that university-based facilities will regularly engage with health departments in pre- and in-service training, advisory and technical assistance, and consultations on the problems of complex children. It is also understandable that there would not be a broad assumption of the service responsibility of the CC network by the UAFs. Further details are provided in the instance of specific programs in North Carolina, Massachusetts, Washington and Ohio.

Table 1. UAF and MCH/CC Linkages 1983

Degree of Involvement:
1 - Periodic
2 - Moderate
3 - Substantial

	Center for Developmental & Learning Disorders Birmingham, AL	UAF-UCI Irvine, CA	Children's Hospital of LA-UAP Los Angeles, CA	Mailman Center for Child Development Miami, FL	Child Development Program Indianapolis, IN
Training					
Shared Trainees	1				
Workshops/Seminars	3		2	2	2
Inservice Provided through Outreach	3	2	2	2	2
Extended Inservice at UAF Site	1		2		
Courses/Lectures	1	1	3	3	
Trainee Practicum or Workstudy	1		1	3	
Trainee Experiences in Clinics/Services	2	2	1	3	2
Service					
Operating Specialty Clinics or Services within UAF	3	3		3	
Staffing State-Operated Clinics	2	3	1		
Follow-Up	3		2	3	
Outreach to Provide Services	3	3	2	2	
Providing Service on Contractual Basis	3	3	3	3	
Providing Services on Referral or Cross Referral for Service	3	3	2	3	3
Advisory					
Special Topic Advisory Committees, e.g., Genetics, Developing Standards	1	3		3	3
Title V State Administering Agency				3	
Crippled Children's Program	2			3	
MCH Program	1			3	
SPRANS Program				3	
Title V Personnel on UAF Advisory Committee	1				
Interagency Committee for Communication or Liaison	2	3	3	3	
Staff					
Employment of UAF Trainees	1		2	2	
Shared or Jointly Funded Staff	1			2	1
Professional Consultation/Technical Assistance	2		1	3	
Planning					
Statewide-Developing Processes or Systems, e.g., Case Management		1		3	
Regional Collaborative Projects				3	
Research					
Utilizing Health Records		3			
Providing Research Data to Effect Changes in System of Services	1	2		3	
Shared Research			1	3	

Division of Developmental Disabilities Iowa City, IA	John F. Kennedy Institute Baltimore, MD	Developmental Evaluation Clinic Boston, MA	UMKC-UAF Kansas City, MO	Meyer Children's Rehabilitation Institute Omaha, NB	Division for Disorders of Development & Learning Chapel Hill, NC	University Affiliated Cincinnati Center for Developmental Disorders Cincinnati, OH	Nisonger Center Columbus, OH	Child Development Center Memphis, TN	University Affiliated Center Dallas, TX	Child Development & Mental Retardation Center Seattle, WA	Waisman Center Madison, WI
1	3	1	3	2		2	3	3	1		3
1		1	2				3				
2	1	1	3				3				
	1						2				
1	2	1		1	3	2	2	3	3	2	3
1	2			2	3	2	2	2	3	2	3
	1		2		3		2				
	1				3	2	2	3	3	1	
2	1	1	3				3				
1	1				3	3		3		3	3
1	3			3	1		2	3	3	3	2
	1	3		2	3	3					
	2						2	3	3	3	3
2	1			3			1				
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Maternal and Child Care Section, State Division of Health Services

A letter of agreement between the DDDL-UAF and the State's Maternal and Child Care Section makes clear the extensive interaction between the two programs.

> The Division for Disorders of Development and Learning... plays a vital part in the state's MCH Plan. The DDDL is a part of the planning process and training, service and/or research role in almost every phase of the Plan's continuum of care concept. Thus, the DDDL is considered not an adjunct, but an integral part of North Carolina's system of services for mothers and children. A specific staff person has been appointed, both in DDDL and in the Maternal and Child Care Section, to assure the appropriate involvement of the DDDL in the planning process and in implementing the block grant.

The relationships described in the agreement are outlined along a continuum of care for the maternal and child life cycle with specific items related to the state's MCH Plan.

Inter-partum Period

The DDDL role in this area is one of generalized training in the area of prevention for physicians, nurses, social workers, and health educators who work in family planning clinics across the state. DDDL staff assisted in the development of a series of "Prevention Workshops" in the area, presenting two in 1981 and one in 1982. The emphasis of the workshops is on the relationship of nutrition, good health care practices and, particularly, genetic counseling services, to raise the consciousness of professionals working in family planning clinics.

Prenatal Period

The MCH plan places emphasis on identifying and serving "high risk" women. Seventeen specialized clinics are available in the state.

Development of adequate genetic counseling is a focus for the current plan. DDDL staff have consulted with the State Perinatal Care Program on the development of criteria to determine high risk, and DDDL research and training concerning the linkage of such criteria to mortality and developmental morbidity have played an important role in the initial development and evolution of the criteria as they are applied statewide.

Currently, the MCH Plan calls for a pilot project on maternal serum screening for neural tube defects which will eventually be a statewide program. Research data on the efficacy of such screening services presented by the DDDL staff have been pivotal in the decision of the Council on Developmental Disabilities to provide pilot project funds.

Neonatal Period

Criteria have been established to provide nursery review of all newborns statewide, and those infants designated as "high priority" for follow-up are entered into a tracking system for the first year of life. The DDDL has been instrumental in the development and application of the criteria and are consulting with DHS staff in evaluating the effects of this service emphasis on newborns.

The MCH Plan also calls for newborn screening for PKU and hypothyroidism. PKU screening services were begun in the 1960s based largely on the research and advocacy of DDDL staff. The DDDL Director was instrumental in securing funds from the Council on Developmental Disabilities so that hypothyroid screening could be begun on pilot basis three years ago. With his assistance, state appropriations have been secured for this service which is now available statewide. Finally, children with PKU receive medical and counseling services at

Chapel Hill. DDDL staff, in conjunction with the Genetics and Metabolism Division of the Department of Pediatrics, provide diagnostic and follow-up services for these children to assure full realization of developmental potential.

Early Childhood (Basic Care):

Each of the state's 100 counties has basic child health services available under the MCH plan. An important component of these services is screening tests for the earliest possible identification of developmental delay. The DDDL staff supports this function by providing training (particularly for public health nurses) in the administration of developmental screening tests and have trained more than 100 nurses and other professionals through regional workshops in recent years. The MCH Plan now includes an emphasis on assisting private physicians in upgrading their abilities in the area of developmental screening and the basic care and management of disabled children. The DDDL has begun development of a curriculum for a short course in the area and contacts are being made with the North Carolina Pediatrics Society to include this course in the Society's continuing education program.

Specialized Care for Children:

The MCH Plan outlines an extensive array of specialized services for disabled children. More than 30,000 children are seen annually in the state's 100 Crippled Children's categorical clinics. An additional 25,000 children with multiple handicaps are seen in the state's 19 Developmental Evaluation Centers (DECs). Finally, Lenox Baker Children's Hospital is a state-operated rehabilitation facility for multiply handicapped children. DDDL staff lend their knowledge and

experience to the development of standards for CC Clinics. Major contributions have been made in the areas of orthopedics and communication disorders, and assistance is planned in the area of neurology.

The DDDL is a full partner in the DEC Program; indeed, the DDDL is one of the 19 DECs. Within this system, the DDDL operates a statewide catchment area, providing direct services in interdisciplinary evaluation, treatment planning, and short-term treatment for approximately 290 children annually. Because of the expertise of its staff and the surrounding services available in the UNC medical center complex, the DDDL serves not only direct referrals, but also other DECs. The importance of this latter role as a tertiary referral resource within the DEC system will continue to grow, particularly as the DECs shift to a heavier load of case management and assume a reduced role of direct evaluation.

Several staff from each of the DECs have received training from DDDL staff in various aspects of developmental disabilities and evaluation of those through short courses/workshops that have been presented regionally. DDDL's training capacity is also lent to other areas of the spectrum of services for disabled children, particularly in the assistance given to the staff of Lenox Baker Children's Hospital. The DDDL pedodontist extends his training and service activities to this hospital on a regularly scheduled basis. In addition, when a new pediatrician joined the hospital staff, he was provided several weeks of inservice training at DDDL to enhance his skills and better prepare him for the special developmental problems of children at the hospital.

Special Areas of Emphasis:

The MCH Plan includes several areas of special emphasis, many of which involve DDDL. To cite just one example, the state is now considering an expansion of its services for the detection and abatement of sources of lead poisoning. DDDL staff sit on an advisory committee to study the problem and alternative approaches to alleviating the problem. Their assistance is particularly helpful in relating high lead levels to potential disability and in advising on methods of modifying or eliminating sources of lead ingestion.

Other SPRANS Programs

The DDDL has linkages with the School of Public Health of the University of North Carolina through both the Department of Maternal and Child Health and the Department of Nutrition. Two members of the DDDL Nursing Section have academic appointments and act as lecturers, supervisors of research projects, and supervisors of occasional short-term trainees rotating through the DDDL from the Department. In addition, there has been some sharing of research activity by DDDL psychology staff, the Department of MCH staff and staff of the Frank Porter Graham Child Development Center. Last year a pediatrician earning his MPH degree (an Army colonel responsible for developmental handicaps among military dependents in Europe) made the DDDL his practicum training site. A similar relationship for another pediatrician, while earning his MPH degree, is also planned. DDDL staff in both nursing and occupational therapy hold MPH degrees from the Department.

The School of Medicine Program for Automated Detection of Neurometabolic Disorders, located in the same building with DDDL, has

long been in the forefront in the development of automated methods for phenylketonuria screening (the photofluorometric method) and other forms of metabolic screening, most recently including hypothyroid screening. Interaction between this program and the DDDL includes use of DDDL clinical material, the work by DDDL medical staff to support the development of statewide screening programs for which the automated technology has been developed in this project, and sharing in research activities leading to joint publications.

The Genetic Diseases Services Project is also located in the same building as the DDDL and interacts closely with DDDL in service, training and research activities. Several joint publications have resulted. DDDL Fellows in Developmental Medicine generally spend a month each year in the program. The Division staff and fellows consult constantly with DDDL staff on the latter's clients. Sharing in management of some of these clients, as with a few recent examples of the Fragile X syndrome, has resulted in furthering the expertise of genetics laboratories and clinical programs in universities outside the state, notably in Georgia and Pennsylvania.

Developmental Evaluation Clinic - UAF
The Children's Hospital
Boston, Massachusetts

The Developmental Evaluation Clinic (DEC-UAF) has had a leadership role in the development and maintenance of consortium projects involving the New England States. The progenitor project for regional consortia is the New England Regional Genetics Group (NERGG), funded by MCH five years ago. Annual meetings of the NERGG bring together the major genetic service providers, state public health planners, relevan

federal personnels, and parent/consumer representatives of the six states.

Four other regional projects have been created in alliance with NERGG: the New England Regional Maternal PKU Project, the Region I Thalassemia Program, the New England Fragile X Syndrome Collaborative, and the New England Regional Maternal Serum Alpha-Fetoprotein Screening Program. The most recent regional effort, the New England Regional Consortium for Lead Poisoning Prevention (NECLPP), is just beginning and is designed on the model of NERGG.

At the request of the Regional MCH office, the DEC and Shriver Center UAF in Waltham agreed to conduct a follow-up symposium on current activities of the MCH Child Development Centers. This symposium (June 16-17, 1983) was a follow-up to one held in 1980.

Department of Public Health, Commonwealth of Massachusetts

The Director of the DEC-UAF has served for the past five years on the Advisory Council (or its predecessor) to the Division of Family Health Services, which is the Commonwealth's Title V Agency. The Council, which has responsibility for consultation in deployment of Block Grant funds, has five committees. The committee for Services to Handicapped Children (SHC) section is chaired by the DEC Director and includes in its membership the DEC Training Director. Committee members have recently made site visits to many CC Clinics in the state in order to develop recommendations on future design and funding of the clinics. The Director of Nursing of DEC is a member of the Division's Early Intervention Advisory Committee.

Among DPH staff are two former trainees of DEC: an MSW in the Division of Family Health Services and the SHC Medical Director, who

maintains involvement with DEC on a weekly basis with the DEC Infant Follow-up Clinic. That clinic, the Feeding Team, and the Down Syndrome Early Intervention Program are all operated out of the DEC. Though no state funding is received, the clinics are viewed as allied services to the Department of Public Health. The Director of the Massachusetts Program for Inborn Errors of Metabolism (and the New England Regional Screening Program) is also a pediatrician in the DEC, and operates the PKU Clinic. The latter provides follow-up approximately on 90% of the newborns identified in the screening program.

The PKU Clinic Director also serves on the state's Advisory Committee on Genetics Services, which counsels the Genetics Unit of DFHS on utilization of monies available under PL 94-278, the Genetics Disease Services Act. The Community Services Unit of the DPH established four pediatric nursing homes, one of which has now been purchased by Children's Hospital, for long term care of multiply handicapped children. Professional services and consultation to the Montrath Pediatric Nursing Home are provided from the DEC-UAF.

Harvard School of Public Health (HSPH)

The DEC Director has previously presented sessions for courses offered through the Department of Maternal and Child Health and Aging--"Content of MCH Services and Programs" and "Issues in MCH Services." In addition, he has now accepted a position as a Lecturer in the Department to conduct courses on the handicapped child. Two recent DEC graduates and two current DEC students have graduated from, or matriculated with, the HSPH, while one HSPH staff member is currently involved in a DEC Fellowship.

Child Development and Mental Retardation Center-UAF
University of Washington
Seattle Washington

The Child Development and Mental Retardation Center at the University of Washington (UW) is a comprehensive training, service and research center. Its Clinical Training Unit (CTU) provides interdisciplinary diagnosis and evaluation and follow-up treatment to children in Region X who have mental retardation and related developmental problems.

Primary Agency Involvement

Regional activities in the areas of interdisciplinary services, training and technical assistance are provided to states in Region X (Washington, Alaska, Idaho) and Montana. These four constitute the WAMI states (Washington, Alaska, Montana and Idaho), an acronym based on the interstate medical training and consultation program started by the UW School of Medicine.

The state agency most intricately involved with the CTU is the Washington State Department of Social and Health Services (DSHS), primarily through its Office of Community Health Services. This Office includes the Maternal and Child Health Program (MCHP), Crippled Children's Service Program (CCSP), Perinatal Program, Genetics Program, and Diabetes Control Program. Services are extended under the auspices of the CDMRC's Mental Retardation Services Project and the Adolescent Services Project, both sponsored by the MCHP.

Interdisciplinary Service Delivery

Service emphasis is on mental retardation and related disabilities, including speech and language impairments, hearing deficits, motor problems, nutrition concerns, learning disorders, and behavioral

pathology. Genetic counseling, family planning, and sex education services for the handicapped are also offered in CTU programs. The CTU audiology program works with the Washington State Crippled Children's Services Program to provide hearing assessment and hearing aids for families who require financial assistance.

The Mental Retardation Services Project is carried out cooperatively between the CTU and the State MCHP. Diagnosis, evaluation and long term follow-up treatment are delivered, within MCHP guidelines, to meet the comprehensive service objectives below:

1) to provide a statewide High Risk Newborn Tracking Program
2) to provide NICU Follow-up evaluation and treatment to infants and children who were cared for in University Hospital's NICU
3) to provide systematic developmental and neurologic long term follow-up for infants with phenylketonuria and hypothyroidism, as detected by the Newborn Metabolic Screening Program of the State Genetics Program
4) to provide specialized interdisciplinary diagnosis, assessment and treatment for infants and children with developmental problems and for whom there are inadequate or non-existent resources in their areas of residence throughout the WAMI region
5) to provide specialized interdisciplinary services which are uniquely available at the CDMRC to children with multiple handicapping conditions.

The NICU Follow-up Program and the State/Regional Teams provide comprehensive follow-up treatment, responding to needs of high risk and handicapped children throughout Region X and beyond. The High Risk Newborn Tracking Program and Metabolic services are limited primarily

to families residing in Washington State.

The Regional Perinatal Care Program (RPCP) is based at the University of Washington and is supported by DSHS through the cooperation of the UW Depart- ments of Pediatrics and Obstretics and Gynecology. The CTU NICU Follow-up Program provides follow-up treatment and evaluation to infants cared for in University Hospital's NICU. Currently about 500 children are participating, while 160 new enrollments are anticipated each year.

Technical Assistance

Technical assistance to the DSHS Office of Community Health Service is ongoing. Current efforts are directed toward the Regional Perinatal Care Program so that NICU follow-up care will be available statewide.

The Maternal and Child Health Program is collaborating with center faculty to develop the Improved Pregnancy Outcome Program. The emphasis will be on statewide intervention with high risk pregnant women and their babies. Efforts are in the areas of staff education, resource development, educating professionals in health care delivery, and support and transportation services to pregnant women and their offspring. Another component will be identifying these high risk women. The program will provide statewide services where no treatment facilities are currently available, with tertiary care centers based in Seattle (UW), Tacoma and Spokane and a specialized secondary center to be located in Yakima. This plan will provide for services in western, central and eastern areas -- particularly in less populated areas where treatment is not yet available.

The DSHS Genetics Program collaborates with CTU faculty in the statewide Metabolic Screening Program for infants born in Washington.

It is legally required that every newborn be tested for both congenital hypothyroidism and phenylketonuria. CTU faculty work with the director of the State Genetics Program and CTU Specialty Clinics provide long term developmental follow-up care for infants and children who have been diagnosed as having these problems. Nutrition faculty at CTU work with the State Genetics Program in both the CTU PKU Clinic and the Biochemical Genetics Clinic. In addition, they also provide nutritional consultation to other genetics programs within the WAMI states.

Though the majority of infants with PKU are patients in the PKU Specialty Clinic, not all infants with congenital hypothyroidism are followed at CTU, but will be evaluated by CTU teams either at CDMRC or in local clinics. Faculty are working with state staff to propose a systematic follow-up service so that these infants can be evaluated during infancy and annually until 8 years of age. Evaluations will focus on cognitive and neurologic status provided by clinics that would be established in eastern, central and western Washington.

The CTU Biochemical Genetics Clinic is the only centralized clinic of its kind in Region X. Technical assistance is frequently provided to WAMI Program staff and to various Crippled Children's Programs in these states. CTU faculty visit these regions regularly to provide genetics services.

MCHP has contracted with CTU nutrition faculty to provide technical assistance and consultation to local public health departments in four Washington counties. In the last quarter of 1983, they presented workshops for more than 300 professionals on PKU screening and follow-up services and on nutrition for handicapped children. A new

project, sponsored by the March of Dimes, provides a nutritionist to evaluate dietary care of premature infants in NICU facilities at University Hospital and COHMC, under the Regional Perinatal Care Program. The nutritionist on that project is surveying infant nutritional needs and conducting studies to define specific dietary adjustments. In addition, she will be designing an education component for advising physicians and parents on appropriate nutritional care of the infants.

Pediatric and social work faculty are providing consultation to the Washington State Crippled Children's Services Program to develop guidelines for staff in the state's neuromuscular centers.

CTU faculty involvement with SPRANS projects includes nursing consultation to Washington State's MCH Program, both through the Mental Retardation Services Project and the Adolescent Services Project. In cooperation with the Washington State MCHP Early Intervention Project located in Lewis County, a nurse is jointly funded to work part time with the Lewis County Health Department and with one of the CTU interdisciplinary teams. The arrangement has allowed for continuity, technical assistance and consultation and has enhanced the quality of both programs.

Other Title V Linkages

An MCH funded program to train nurses to care for children with handicapping conditions is directed by the head of CTU's Nursing Discipline. The program enhances the center's linkages with nurses at city and county levels and with the agencies through which their services are provided. Members of the nursing staff are also currently working with the State Genetics Programs in Washington and in Ohio,

looking at public response to genetics evaluation materials distributed with marriage licenses. The UAF director is on the Advisory Committee of the Washington State Diabetes Control Program, providing consultation relative to pregnancy outcome in diabetic women.

University Affiliated Cincinnati
Center for Developmental Disabilities-UAF
Children's Hospital Medical Center and
The University of Cincinnati
Cincinnati, Ohio

When asked about the relationship between his agency and the UACCDD-UAF, the response of the Ohio Title V agency director was that, "It couldn't be any closer." Regarding what incentives state programs and UAFs have to enter into such agreements, he concluded that "The population benefits more than if the UAF and MCH are working separately. The UAF provides expertise and MCH pays that back in part by providing patients essential to the UAF for service, training, research and professional publications. The net result is far superior than if both were working alone."

The following lists are of Title V programs with which the UACCDD-UAF has working arrangements and the Title V related coordination or linkage activities with each.

Title V Related Programs	UACCDD Coordination/Linkage Activities
Within CHMC	
Adolescent Clinic and Training Program in Adolescent Health Care	Adolescent DD Program
Children's Dental Care Foundation Dentistry for Handicapped program	UACCDD Department of Pediatric Dentistry provodes dental outreach services

Children's Dental Care Foundation Craniofacial Anomaly Team	UACCDD and Applied Research Lab/Genetics Counseling Regional Center (ARL/GCRC) staff/trainees consultation/ participation and referral to and from UACCDD and ARL/GCRC
Division of Inborn Errors of Metabolism	Metabolic Disorders Treatment Program (MDTP); Chromatography/Enzymology Lab studies for UACCDD; component of ARL/GCRC; Shared Research
Newborn Division (Training in Perinatal Care & Research) Regional Perinatal Team Improved Pregnancy Outcome	Newborn High Risk Early Intervention Program; UACCDD, MDTP/Myelomeningocele Program, staff/trainee consultation to Newborn Nurseries & referrals of infants to UACCDD programs
Mental Retardation Research Center (MRRC/IDR) including Division of Human Genetics, Teratology/Cytogenetics and Inborn Errors of Metabolism	ARL/GCRC and special laboratory studies (e.g., tissue culture for UACCDD); IDR Research Seminars; UACCDD Research Advisory Committee; MRRC/IDR Executive Committee; Shared Research
<u>Outside CHMC & UC Medical Center</u>	
Maternal & Infant Care (Cincinnati Health Dept. M&IC)	M&IC works with UACCDD ARL/CDRC for prenatal program and inservice training of M&IC staff; M&IC collaborates with High Risk Early Intervention Program; M&IC Director serves as liaison between UACCDD and Cincinnati Health Dept.; Director of Cincinnati Health Dept. Handicapped Children's Registry serves 1/2 time at UACCDD as liaison with Cincinnati Public Health Nurses.
Ohio Department of Health/ MCH-BCCS	MCH funding support of ARL/GCRC in statewide genetics network; MCH grant to UACCDD Myelomeningocele Program for outreach/inservice to primary care provider; BCCS third party payment for UACCDD clients; UACCDD inservice training of Health Department and related Title V staff, e.g. UACCDD participating in Nursing Child Assessment Training NCAT) for PHN's; BCCS is a member of UACCDD LIC and Ohio Consortium State Advisory Committee; Ambulatory Health Care Accreditation of UACCDD; UACCDD member of MCH/BCCS Committees on Myelomeningocele Standards, Cerebral Palsy Standards, DD

	Nursing Care Standards; Title V Advisory Committee to UACCDD & Letter of Agreement is being prepared by Ohio Department of health
Other, local, state, regional national Title V related programs	4 of 35 UACCDD trainees with 160 or more contact hours from FY 82 are employed in Title V-related activities; 6 continue as trainee consultants at UACCDD; 7 are employed in other health agencies or universities; 8 are in private practice; and 5 are in public/private schools. Clients accepted from Ky. and Ind. crippled children's programs.

A Look at the Future for Alliances

There are a number of affirmations and policy formulations which have emerged in the past year from various conferences and projects, which speak to more coordination and outreach by the MCH/CC service system. It is reasonable to assume that University Affiliated Facilities will have an increasing alliance with CC programs as the scope of these becomes more broad. The traditional role of UAFs in the facilitation of multi-faceted care programs for handicapped children provides a natural base for assistance in health department programming. Note particularly the affirmation of Magrab regarding UAF membership in the community team. UAFs look forward to enhanced partnership in the evolving designs inaugurated by CC programs. The seven excerpts that follow are representative of these.

> There is a need to structure a community-based system to coordinate the evaluation and planning of services for the fifteen percent of disabled children who have complicated or multifaceted disorders and to recognize that this entails more than medical or nursing care. There must be a smooth flow of information between all social, medical, educational, and family concerns; responsibility and accountability for providing and following up on services must be assigned and accepted.
>
> There must be a realization by all the remaining service providers, health planners, legislators, and health financiers, that such community-based evaluation and planning is necessary if barriers to maximum achievement for all disabled persons are to be removed.
>
> There is no one uniform formula to guide individual communities toward such a system. Each state must review its individual communities toward such a system. Each state must review its individual health, education, and social service state plans that meet the state's individual geographic, political, and demographic needs; each state must work cooperatively to create a community-based system for those disabled children who require a coordinated evaluation and planning function.
>
> from: Healy, A.
> "Children with Disabilities: Implication For Care"
> Report of the Surgeon General's Workshop on Children
> With Handicaps and Their Families
> U.S. Department of Health and Human Services
> The Children's Hospital of Philadelphia
> December 13th and 14th 1982

Individualized Service Plans and Coordination of Care. Access to needed services will be best assured with the development of an individualized service plan for each child and family. The plan, developed in coordination with the family, should outline services to be provided to the family, including not only medical and surgical services, but also attention to education, family support, counseling, and the like. The plan should have clear and explicit allocation of responsibilities to providers or agencies for carrying out elements of the plan, and should allow for periodic monitoring and updating.

Each plan should define a specific person to be the coordinator of care for the child and family. Many different types of people can provide care coordination for a family, including family members themselves, social workers, lay counselors, physicians, school personnel, and others. Who provides the service is much less important than that the function of care coordination be carried out by someone.

from: Ireys, H.T., Moynihan, L.C., Perrin, J.M., and Shayne, M.W.
"Chronically Ill Children in American:Background and Recommendations"
Center for the Study of Families and Children
Vanderbilt Institute for Public Policy Studies
April, 1983

In developing a community team, usually one or two groups may take the lead in organizing a community effort and invite others to participate. Key participants that should definitely be included are those which have federal mandates for serving handicapped children. They have varying names in different communities but usually they are the following:

1. Local Department of Education: Division of Special Education
2. Title V Programs (i.e., Maternal and Child Health Programs, Crippled Children's Services, Handicapped Children's Program)
3. Local Title XIX (Medicaid/EPSDT) and Title XX Programs
4. Department of Health and Human Services Agency serving Developmentally Disabled Individuals
5. Head Start

The following others are active in providing service to the target population and should also be included:

1. Mental Health Centers
2. University Affiliated Facilities (UAF)
3. Resource Access Projects (RAP)
4. Community medical leadership

5. Preschools and day care centers, including handicapped children's early education projects
6. Parent, foster parent and citizen organizations
7. Other local providers and other referral sources.

from: Magrab, P.
"Community Support system for Programs Serving Handicapped Children and Their Families"
Community Comprehensive Health Programs Serving Handicapped Children
The Johns Hopkins University
School of Hygiene and Public Health
January 20-21, 1983

The system should be based on the previously referred to "principles of good care" to provide services for handicapped children.

The system should be designed by representatives of professional groups involved with providing services for handicapped children.

The system should not be made by disbanding the current programs that provide services, but by identifying the role of each and determining how each program can function cooperatively.

The system need not require the consolidation of federal agencies or state programs. Rather, it should propose methods whereby patient services can be integrated at the community level.

The system should describe a three-tiered system of care that will, in general, be comparable to the three-tiered system of American medical care.

The system should be designed so that patients will not only have easy access to the system but can easily move from one level of care to another as their needs for services change.

The system should describe methods of creating inter-professional and inter-agency relationships to assure that the three-level system of care will work to the advantage of the patient.

The system should describe a community-based system that involves both health and educational personnel to provide services for children with educationally related health problems.

The system should recognize the special role of the state crippled children's program in the provision of the coordinating services described in the "principles of good care."

from: MacQueen, J.C.
"The Health System Required for a Comprehensive Program Serving Handicapped Children in a Community"
Community Comprehensive Health Programs Serving Handicapped Children
The Johns Hopkins University
School of Hygiene and Public Health
January 20-21, 1983

The State CC programs should assure the accessibility, availability and quality of health care for children with handicaps, by effectively carrying out the important functions of 1) needs assessment; 2) planning and evaluation; 3) standard-setting; 4) quality assurance; 5) provision of technical assistance; 6) program administration/management; 7) coordination
and linkage development and 8) provision of health care services to those children who do not have access to such care.

Since the State health agency usually has responsibility for collecting, recording and analyzing population and demographic data, socio-economic data, health status information, health services and resource data, and other such data for the entire State, the State MCH and CCS programs have access to a broad range of information which can be used to identify needs, establish priorities and plan/implement programs and services for child health.

from: McPherson, M.
"Concept and Rationale for a Comprehensive Community Program for Handicapped Children and Their Families"
Community Comprehensive Health Programs Serving Handicapped Children
The Johns Hopkins University
School of Hygiene and Public Health
January 20-21, 1983

What changes have occurred in your State that are directly attributable to your project?

Several States reported the development of interagency agreements, which outline the process for identifying, evaluating, and providing appropriate services to high risk infants and young handicapped children.

A computer resources file for Statewide services to handicapped children which is accessible to schools and other agencies was established in one State. In another, interagency groups have been formed in conjunction with regional clinics to improve services to the clinics through interagency collaboration. Physical therapy contracts were established in a State between a Crippled Children's program and local education agencies to provide therapy to children during school.

State collaborative project staff have served on local interagency advisory groups which resulted in funding of grants for local projects. Workshops and inservice training and education were offered in several states to educators, health providers, agency staff, and parents. Interdisciplinary staff development was noted as a key accomplishment by several respondents. One project developed new strategies for teaching transitional readiness skills in math and reading which are being used in other preschool programs.

In one State, children now have access to comprehensive diagnostic evaluation and case planning services, within fifty to seventy-five miles of their homes, for a variety of health and educational problems.

Some States noted increased cooperation between health, education, and social service agencies. This includes the development of trust, a willingness to set aside "territorial" differences, and mutual cooperation in coordination of services for children. In one State, a Statewide task force was convened to identify and resolve issues which impede the delivery of coordinated, comprehensive services to handicapped children. One State legislature transferred some unallocated funds to the interagency collaboration effort, marking the first time it had made a direct financial commitment to a program. One State health agency reported that it will have a representative serve on a legislative advisory committee on proposed changes in P.L. 94-142.

Some States reported that coordinated community/Regional approaches to comprehensive services are replacing networks of fragmented services. Frequent community resource team meetings and other cooperative mechanisms are promoting communication between health professionals, educators, and other agency representatives. High risk children are being referred earlier for community services.

Finally, a form which could be used by parents or professionals to collect a cumulative history of a child's journey from agency to agency was developed by one of the projects. Another form developed targets the exchange of information between educators, physicians, and allied health specialists. Most of the States reported increased and

improved contacts between agencies, programs, and professionals in the promotion of interagency collaboration efforts.

from: Professional Management Associates, Inc.
"Cross-cutting Issues in Six State Collaborative Projects"
O.M.C.H.
September 30, 1982

We recognize that there are unmet needs in Maternal and Child Health and support these new or continued areas of effort (not listed in any specific order):

A. MCH public education
B. Data collection and analysis (especially outcome measurement)
C. Technical assistance for MCH/CC program managers. The requesting agency should be able to participate in the selection of the consultant.
D. Environmental risk reduction (accident prevention).
E. Community-based family support services.
F. Health promotion and prevention in keeping with the HHS Secretary's emphasis.
G. Integration of services for children at the state and local level: e.g., health and education
H. Development of models/strategies to assess third party reimbursement for MCH services.
I. Role of local governments (in the context of the block grant) in the provision of MCH services.

from: Association for MCH/CC Programs
"Statement on Development of Sprans Policy During FY 1983-1984"
November 19, 1982